

HELP AND HOPE

FAMILY RESOURCE GUIDE



Connecting
Families to
Resources

for

Infants &
Young
Children

Who are
Deaf

or

Hard of
Hearing

Idaho Council for the Deaf and Hard of Hearing
in cooperation with the
Idaho Newborn Hearing Screening Consortium



Idaho State Council for the Deaf and Hard of Hearing

In cooperation with the
Idaho Newborn Hearing Screening Consortium

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HELP AND HOPE

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The **Idaho Council for the Deaf and Hard of Hearing** expresses gratitude to their many partners for sharing their expertise, time, and energy to develop this updated parent resource guide, **Help and Hope**. The Council resources that have contributed to this guide include two full time Council staff and four part-time staff devoted to administering and implementing the four-year grant for Early Hearing Detection and Intervention designated as **Idaho Sound Beginnings**. The partners include the staff of many agencies that form the Idaho Consortium for Newborn Hearing Screening, most importantly the Idaho Infant Toddler Program, the Idaho School for the Deaf and the Blind, the Idaho Hospital Association, the Idaho Chapter of the American Academy of Pediatrics and the voluntary members of the EHDI Advisory Committee. This resource guide reflects their commitment to provide a broad scope of information about early intervention services and other related services to families.

Special appreciation is given to **Mary Reis**, who developed the original parent resource guide, titled “Silence” dedicated to her son, Dustin. When the Council published that guide it was given the title of “Help and Hope, A Resource Guide for Parents.” The addition of new resources and publications referenced in this guide have changed the look of the original publication of “Help and Hope.” Mary’s efforts to help parents discover resources and information were driven by the lack of available resources in 1995 and she can be proud that she was a pioneer in developing such a resource. Although this edition of Help and Hope looks very different, we have attempted to continue the positive spirit of that first version.

Special thanks to Cynthia Carlin who orchestrated and integrated the editing of this parent resource guide. This was not an easy task given that there were multiple editors constantly making comments and suggestions for changes or additions.

We salute the generosity of other organizations that whole-heartedly allowed Idaho to use their excellent reference and resource materials, in total or in excerpted format. We give credit throughout the book; however **we list below our major contributors:**

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The Council for the Deaf and Hard of Hearing expects to update this parent resource guide as needed. An electronic copy is available on the Council's website: www.state.id.us/cdhh

FOREWORD

By Pennie S. Cooper
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Idaho Council for the Deaf and Hard of Hearing

Over 24,000 children are born every year in the United States with some level of hearing loss. The number of infants, in Idaho, who were diagnosed with significant hearing loss in 2001 was 48 and in 2002 it was 33. Studies have shown that the earlier a child is identified with a hearing loss and begins early intervention, the more likely they are to develop language and communication skills on a par with their hearing peers, and lead full and productive lives.

While at this time over 38 states have enacted legislation to accomplish early hearing detection and intervention; the Idaho Newborn Hearing Screening Consortium and the Council for the Deaf and Hard of Hearing have worked toward the adoption of a voluntary system. With the endorsement of the Idaho Hospital Association, every birth hospital in Idaho has committed to the policy of hearing screening for all newborns. Through the seven years work of the Council and the Idaho Consortium for Newborn Hearing Screening, a system for audiological diagnosis, early intervention, medical management and family support is operating with the goal of providing the best services possible at the earliest time in these infants' lives.

Newborn hearing screening makes a difference for all children and their families. Information about hearing and typical hearing milestones is valuable for all parents in the care of their child. One of the nation's, and Idaho's, goals is to confirm hearing loss by three months of age, with appropriate intervention by six months of age. Early detection of hearing loss in an infant, early medical management if needed, and the initiation and follow-through of early intervention and treatment before six months of age has been shown to be highly effective in promoting a child's development. **Early intervention services, as desired by the family, should begin as soon as possible.**

Help and Hope, is a parent resource guide based on the following values and beliefs:

A child with a hearing loss and his or her family should have access to:

- ♦ Assessment, diagnosis, and intervention as early as possible.
- ♦ Family-centered programs that provide early language acquisition.

- ◆ Information about where to receive audiological and medical services.
- ◆ Natural language development through visual, verbal and/or auditory channels as early as possible.
- ◆ A linguistically rich environment.
- ◆ Early intervention services planned and delivered by qualified personnel, proficient in the family's primary language and communication and in collaboration with the family.
- ◆ Early intervention services that embrace high expectations, standards and evaluation criteria.
- ◆ A voluntary statewide, parent-driven, parent-to-parent support system.
- ◆ The most current resources and assistive technology.

Whether you are a parent, sibling, school administrator, teacher, audiologist, physician or someone else related to the community of deaf and hard of hearing individuals, ***Help and Hope*** is for you because...

“Some babies are born listeners...others need your help.”



Photo reprinted courtesy of NCHAM

Editor's Note

Help and Hope is primarily written to and for parents. Some sections were adapted from other sources such as the Boys Town Research Hospital and the National Center for Hearing Assessment and Management (NCHAM). Because of the different sources used and the context of the information, the grammatical structure of the text uses a mixture of first, second and third person pronouns, depending on who is speaking to the reader. A section written by parents writing to other parents, will use a different structure, and have a different tone, than a section written by an audiologist or early interventionist conveying educational information for the parents' use.

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INTRODUCTION TO HELP AND HOPE, a Parent Resource Guide

This resource guide, *Help and Hope*, is primarily written to and for Parents. It is however, also a useful resource for Teachers, School Administrators, Audiologists, Early Intervention Specialists, Physicians, Speech and Language Pathologists, or anyone interested in learning about deafness or hearing loss!

Parents can use it to:

- ◆ Understand the importance of early identification of hearing loss and the critical nature of early intervention.
- ◆ Understand that they have many choices for their baby and that they have the flexibility to explore the options and make changes when necessary.
- ◆ Learn how to connect with other families of children who are deaf or hard of hearing for support.
- ◆ Read comments from and be encouraged by the experiences of parents who have traveled the same road with their child who is deaf or hard of hearing.
- ◆ Explore choices for communication methods.
- ◆ Find out about services and supports available to families and to professionals.
- ◆ Get information on resources, including financial assistance.
- ◆ Learn about the rights of individuals who are deaf or hard of hearing and how to advocate for them.
- ◆ Discover community support systems, resources and service programs.

The Council for the Deaf and Hard of Hearing became concerned about the lack of early identification of newborns with hearing loss and began working with other organizations to form the Idaho Newborn Hearing Screening Consortium in the fall of 1995. At that time no hospitals were providing hearing screening for all newborns. Through the efforts of the Council and the Consortium, by January of 2003 all birthing hospitals in Idaho have programs to screen newborns for hearing loss. The first hospital programs to begin screening all newborns for hearing started in 1996. The first edition of "Help and Hope" was published in 1997 and was made available to hospitals, parents, audiologists, early interventionists, and the Parent/School Advisors at the Idaho School for the Deaf and the Blind.

Along with the advent of newborn hearing screening and the early identification of babies with hearing loss, it became evident that a system was needed to assure that diagnostic services were provided and that a referral to early intervention services be assured if the baby is diagnosed with a hearing loss.

In March of 2000, the Council for the Deaf and Hard of Hearing was awarded a four-year EHDI grant from the U.S. Department of Health and Human Services. This grant provided funding to help all hospitals purchase newborn hearing screening equipment, to develop a data tracking and management system to identify babies referred for diagnostic evaluation, to develop a system for immediate referral to Early Intervention, and to help develop resources to assist the family and the newborn receive needed Early Intervention Services.

For families of babies newly identified as being deaf or having hearing loss, important first steps include receiving information about their child's hearing loss and the opportunity to be connected to other families for information and support.

The Idaho Council for the Deaf and Hard of Hearing received a grant from the Idaho Children's Trust fund in 2002 to begin formal development of ***Idaho Hands & Voices***, parent-to-parent support organization, with parent consultants in seven different regions of the state. A second year of funding is providing additional funds to support the further development and the activities of the organization through June of 2004. Hands & Voices can connect you to other families with deaf or hard of hearing children, who are available and willing to listen to your concerns and offer their understanding and wisdom. Most parents whose baby has been identified as having a hearing loss or deafness will receive information about Idaho Hands & Voices. If you do not receive information on Hands & Voices, please ask your early intervention specialist for referral to your local "Hands & Voices" representative, or contact the Council for the Deaf and Hard of Hearing for referral information (see the resources section).

As you read through this resource guide you may discover questions and ideas you have not considered as you explore opportunities to enhance the quality of life for your child who is deaf or who has hearing loss. Remember -- the options and decisions facing any family are theirs to make with information and support from knowledgeable professionals and parents. There is no one "right way" when it comes to finding the program that will empower a child to success. His or her unique needs, as well as the needs of the family, will change with time and it is very important to see this continuum as a work in progress. As you begin this journey, as or with a family, we extend our heartfelt support and hope this parent resource guide does provide Help and Hope.



Discovering what works is what makes the choice right!



NEWBORN SCREENING

What is Newborn Hearing Screening (NHS)?

Simple, inexpensive and safe tests are available in all Idaho birth hospitals to screen newborns for hearing. The tests are important because *much can be done* if hearing loss is identified early in a baby's life.



The goal is to test all newborns before hospital discharge regardless of whether they are in newborn intensive care units or in the regular nursery. Federal funding assists states to detect hearing loss and provide appropriate intervention services. The programs are known as Early Hearing Detection and Intervention (EHDI) programs. If a hearing loss is detected, the next step is to provide intervention services, which may include hearing aids or hearing devices, sign language classes for the parents, and services to support the family and baby in learning communication skills. Babies, not born in a hospital, can receive a hearing screening, without charge, at any of the regional Idaho Department of Health and Welfare Child Development Centers. (See the *Resources* section for a listing of regional centers)

Why is Newborn Hearing Screening Important?

Detecting hearing loss early is important since babies quickly start to learn language. Listening in the first few months of life prepares the baby to learn language. If the baby does not hear, then language development can be delayed.



By the first birthday, infants without hearing loss are already figuring out what words mean. Before their first birthdays, they babble many of the sounds they hear spoken around them. These early steps are building blocks for communication.

Babies learn language by tuning in to family talk whether it is words or signs. If a baby has an unidentified hearing loss it may lead to slow development of language and create difficulties in family communication. Delays in speech and language can also lead to school problems, both academic and social. The early identification of the hearing loss and the provision of intervention services can help prevent these delays.

Hospitals routinely screen babies for several specific problems. *Interestingly, hearing loss occurs more often in babies than any of the other problems that are screened for at birth.*

Approximately one to three babies out of 1000 will be born with permanent hearing loss. Because early identification is important all Idaho birth hospitals are participating in hearing screening programs.

What causes hearing loss in newborns?

A baby can have a hearing loss even if no one else in the family has a hearing loss. Over 90% of children with hearing loss are born to hearing parents. There are many possible causes in infancy, including:

- Prematurity
- Medications or drugs
- Infections
- Exposure to chemicals and other toxins during pregnancy
- Genetic factors

Sometimes the cause of a baby's hearing loss can be identified but other times, the cause may not be clear. If your baby has a hearing loss professionals can work with you to explore the possible cause. In some cases there is no definitive answer and nearly 50% of infants with hearing loss have no known risk factors or genetic condition to explain their loss.

Can my child pass the hearing screening at birth and still have a hearing loss?

Some hearing losses are congenital, that is, occurring before or during birth. Other hearing losses are acquired; this is, occurring after birth. Acquired or late onset losses can be due to the effects of illnesses or risk factors such as the use of certain antibiotics. Some acquired losses may be genetic losses of a progressive nature, and will not be detected until later. If your child has any of the risk factors listed below, his or her hearing should be monitored regularly even if the screening at birth did not indicate a hearing loss.

What is a "risk factor"?

A "risk factor" is a medical condition or event that is known to be associated with hearing loss. The presence of a risk factor does not guarantee that a hearing loss is inevitable; it does mean that a hearing loss was an outcome in an unusually high number of children with one or more of these specific conditions. The list of hearing loss risk factors includes the following:

- Family history of childhood hearing loss,
- Infection during pregnancy (rubella, cytomegalovirus/CMV, syphilis, herpes, or toxoplasmosis),
- Anomalies of the head and neck (e.g. malformed outer ear),
- Low birth weight (under 3.3 pounds),
- Hyperbilirubinemia (jaundice), at levels requiring blood transfusion,
- Bacterial meningitis,
- Ototoxic medications,
- Mechanical ventilation (respirator) for more than five days,
- Apgar scores of 0 to 4 at one minute or 0 to 6 at five minutes.



WHAT DO I DO NOW?

"YOUR CHILD HAS A HEARING LOSS"

Even though you may have suspected there was a problem, hearing a doctor or audiologist say, "Your child has a hearing loss", may have come as a shock to you. Most people do not know much about hearing loss and what it means for their child and family. As the professional who delivered this news to you talked further, you may not have heard much of what he or she was saying. In your mind, questions may have started to churn:

"Can it be corrected?"

"What caused it?"

"Will it get better?"

"Will it get worse?"

"Can he learn to talk?"

"Can she go to regular school?"

"If we have more children, will they be deaf, too?"

"Can he get married?"

"Will she be able to get a job?"



The answers you get to some of these questions may not be what you want to hear:

"No, this type of hearing loss cannot be medically or surgically corrected." Or-

"We don't know for sure what your child's future holds – it depends on a lot of things."

You want the best for your child and now, you are not sure you know what to do.

In the days and weeks following the diagnosis of your child's hearing loss, you may feel like you are on a roller coaster. Your feelings may swing from despair to hope, from sadness to anger, from feeling incompetent to feeling confident. As you carry out your daily routines – finishing a chore or arriving at a destination – you may realize that your mind was somewhere else, thinking about your child and what you should do. You may also find within yourself unexpected sources of strength to do what has to be done in spite of feeling that you are living under a cloud.

The professionals who evaluate your child's hearing will have recommendations for you: see an ear specialist, meet with early intervention professionals, have more testing done. As you follow these recommendations, you will meet people who can help answer your questions and explain the decisions you must make. The information they give you and opinions they express may also create more confusion for you!

One of the most difficult areas for family members following the diagnosis of their child's hearing loss is having to make decisions while knowing they don't have all the information. For instance, you may be getting conflicting opinions and information from different professionals about what you should do. Which recommendation is right for your family? You may be frustrated by recommendations that seem impossible to carry out. You may feel there is not enough time in the day or money in your bank account to do what you are told "should be done."

WHAT SHOULD WE DO?

One thing most families want to do is gather information that will help them make good decisions for their child and family. Other parents of children with hearing loss are almost always happy to share their experiences and to tell you who and what have been most helpful to them.

(See the Resources section for information on finding parent support in your area.)

There is no one course of action that is right for every family. Only you can define what is right for you and your child. And what is right today may not feel right in six months. Keep in mind that almost every decision you make can be changed down the road. Knowing that most of the decisions you make today do not have to last forever takes some of the pressure off.



Communicating with your baby is a joyful experience.

Whether or not your baby has a hearing loss, every baby needs lots of love and attention.

Newborns need to be held, to have you look directly into their eyes, and to speak to them in soothing tones.

Even babies who can't hear you respond to your touch and your eyes.

Communicating using your voice, touch, and facial expression are important ways of interacting with your baby.



WHAT ARE SOME OF THE IMPORTANT DECISIONS I WILL HAVE TO MAKE?

There are many decisions ahead, but thankfully you won't be asked to make them all at once. Normally, shortly after a child's hearing loss is diagnosed, a number of professionals begin working with your family to provide support and help you figure out what you need to do next. Your baby's doctor will help guide you through ongoing care. Your doctor and a hearing specialist called an audiologist will work together and make referrals for further medical care soon after your baby's hearing loss is confirmed. Some of the people who might become involved with your family at this time include:

- Pediatrician or a Family Practitioner
- Ear, Nose and Throat Physician
- Other parents
- Pediatric Audiologist
- Early Intervention Specialist
- Speech-Language Pathologist
- Genetic Professionals

The role of each of these professionals is described in the next section- *Who Can Help*.

A medical evaluation is important for every baby who has a hearing loss. This evaluation helps to:

- Identify the cause of your baby's hearing loss
- Determine if your baby has any other medical problems
- Form recommendations for your baby's ongoing health care.

An ENT, or otolaryngologist, is a doctor who specializes in evaluating and treating ear diseases. All babies with hearing loss should be referred to an ENT. As part of the evaluation, your baby will have a physical exam and may have laboratory tests and/or special x-rays.

All families with a baby who has hearing loss should be offered a referral for genetic counseling, evaluation, and services. Genetic professionals may be able to provide information about the cause of hearing loss, possible associated medical conditions, and the risk of hearing loss for other family members.

For a child with a hearing loss, it is essential that early intervention begin as soon as possible. Early intervention and what it means for your child and your family is discussed at length in the *Early Intervention* section.

Because each child and family situation is unique, it would be nearly impossible to try to list all of the decisions that you will be faced with. Some of the most common ones include:

- Amplification (hearing aids and other listening devices)
- Cochlear Implants
- Communication Options
- Educational Placements



Your Rights as a Parent:

If you are to become an effective advocate for your child, you must first know your rights, and the rights of your child. This information can be found in the *Your Rights as a Parent* section.

One Step at a Time:

While the thought of having to make so many decisions for your child may be overwhelming, remember that most do not need to be made immediately. First and foremost, don't forget that you need to give yourself time to be able to accept your child's hearing loss and adjust to the changes that it might mean for your family. Once you have begun to do this, you will be able to start to educate yourself and move towards making the decisions that need to be made.



WHO CAN HELP?

You will meet new people as a result of your child's hearing loss. Some of these people will be medical professionals, some will be parents and caregivers of other children with impaired hearing, some will be educators, and some will be audiologists. Here is a brief description of ways in which each of these groups may be of help to you.

Pediatrician/Family Practitioner

Your child's primary care physician can help by:

- ❖ Referring you to an audiologist skilled in testing the hearing of infants and toddlers when you express concern about your child's hearing.
- ❖ Answering your questions about medical or surgical treatment of different types of hearing loss.
- ❖ Confirming the need for prompt action involving amplification and early intervention once your child has been diagnosed with hearing loss.
- ❖ Putting you in touch with early intervention programs.
- ❖ Treating your child – or referring to ear specialists – when your child has middle ear disease that increases his/her degree of hearing loss.
- ❖ Serving as your child's 'medical home', coordinating all of your child's health services.

Audiologist

The audiologist can help by:

- ❖ Having the appropriate equipment (Visual Reinforcement, Audiometry, and Tympanometry) and the skills to test the hearing of infants and toddlers.
- ❖ Obtaining complete information about your child's hearing in each ear at a range of frequencies.
- ❖ Carrying out – or referring infants or difficult-to-test children for Otoacoustic Emissions (OAE) testing and Auditory Brainstem Response (ABR) testing, when necessary.
- ❖ Recommending appropriate amplification.
- ❖ Keeping your child equipped with well-fitting earmolds.
- ❖ Testing your child while wearing amplification and questioning parents about child's responses to sounds at home.
- ❖ Giving you information about early intervention programs available to your family.
- ❖ Working in partnership with you and early intervention specialists to monitor and maintain your child's amplification system (Hearing aids, FM systems, cochlear implants)
- ❖ Testing and monitoring your child's hearing on a regular basis.

Otolaryngologist or Ear, Nose & Throat (ENT) Physician

The ENT can help by:

- ❖ Confirming that there is not a medically treatable condition in your child's outer ear or middle ear that is causing the hearing loss.
- ❖ Answering your questions about medical or surgical treatment of different types of hearing loss.
- ❖ Scheduling further procedures to rule out other causes of hearing loss.
- ❖ Signing a form authorizing use of hearing aids with your child (required by law in some states before hearing aids can be fit on a child).
- ❖ Placing ventilation, or PE, tubes in your child's eardrums if he has chronic middle ear disease that is not resolved by antibiotics in a timely way.

Other Parents of Deaf/Hard of Hearing Children

Other parents can help by:

- ✧ Sharing experiences they have had with professionals and early intervention programs.
- ✧ Telling you about people and information sources they have found useful.
- ✧ Listening to you.
- ✧ Sharing with you their feelings related to parenting a child with hearing loss and how their feelings have changed over time.
- ✧ Telling you about their child's achievements.
- ✧ Getting together with you so your children can play together.

Early Intervention Specialist for Deaf/Hard of Hearing Infants & Toddlers

The Specialist/Educator can help by:

- ✧ Describing the services offered through their early intervention program and costs, if any associated with services.
- ✧ Describing how your family members will be involved in early intervention services: defining your roles in early intervention and their expectations about your family's participation.
- ✧ Answering, when possible, your questions about how your child's hearing loss will affect his ability to learn, to communicate, and to participate in school and society.
- ✧ Discussing with you how both your child's strengths and needs and your family's strengths and needs will be assessed and when these assessments will take place.
- ✧ Giving you a time line for when services will begin and end.
- ✧ Describing how you and other caregivers will be given opportunity to acquire information and skills that will help you promote your child's development of listening and communication/language skills.
- ✧ Listening to your observations and concerns about your child and discussing these with you.
- ✧ Working with the audiologist to help your child learn to use amplification and make sure the child's hearing aids function properly.
- ✧ Keeping records of child's progress in acquisition of listening skills.
- ✧ Providing you and your child with high-quality, individualized early intervention services that lead to your child acquiring listening and communication/language skills.
- ✧ Giving you support during difficult times
- ✧ Working with you to define your child's educational needs when your child is ready to "graduate" from early intervention.

Speech-Language Pathologist



The speech-language pathologist can help by:

- ✧ Evaluating receptive and expressive communication skills and providing services to develop or improve receptive or expressive communication.
- ✧ Providing treatment focusing on comprehension of language in oral, signed, cued or written modes.
- ✧ Providing treatment dealing with speech and voice production.
- ✧ Providing treatment in auditory training, speechreading, and communication strategies.

Genetic Professionals

Clinical geneticists (physicians) and genetic counselors can provide a genetic evaluation that includes:

- ✧ Reviewing your family and medical history and performing an examination if necessary
- ✧ Discussing laboratory tests, including DNA or chromosome testing that may be recommended

Source: "For Families Guidebook" Schuyler, V. & Sowers, J. (1998).
Hearing & Speech Institute, 3515 SW Veterans Hospital Road, Portland, OR 97201.

Help and Hope - 2003

A MEDICAL HOME FOR EVERY CHILD IN IDAHO

Several years ago, the American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau of the U.S. Department of Health and Human Resources began promoting the concept that every child in America should have a **medical home**. The AAP defines a medical home as the following:

"A medical home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician whom they trust. Pediatricians and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential. . . where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent."

In other words, every child should have a primary health care provider who knows that child individually, cares about him or her, is aware of his or her medical needs, and is capable of providing culturally sensitive and appropriate medical services. The concept is a little difficult to define in operational terms, and we are still a long ways from achieving the goal that every child has a medical home.

The Maternal and Child Health Bureau, as a part of their efforts to promote universal newborn hearing screening, diagnosis, and intervention, has encouraged that early hearing detection and intervention services be linked with a medical home. In a copy of guidelines for applicants competing for funding, The Maternal and Child Health Bureau outlined that a "medical home" for children with special health care needs and their families should reflect the following elements (American Academy of Pediatrics, 1997):

1. The provision of preventive care;
2. The assurance of ambulatory and inpatient care, 24 hours a day;
3. Strategies and mechanisms to ensure continuity of care (from infancy through adolescence);
4. Identification of and medically appropriate use of subspecialty consultation and referrals;
5. Interaction with school and community agencies; and
6. Maintenance of a central record and data base containing all pertinent medical information, including hospitalizations.

Learn more about the concept of a medical home at The National Center of Medical Home Initiatives for Children with Special Needs, housed within the American Academy of Pediatrics (www.aap.org).

Hearing & Language Milestones



• Birth to 3 Months

- startles to a sudden, loud sound
- soothes or calms to your voice



• 3-6 Months

- turns head or moves eyes to a familiar voice
 - watches a speaker's face
- enjoys rattles and other sound making toys
 - plays at making noises and sounds

• 6-9 Months

- responds to soft level of speech & sounds
 - responds to his/her own name
- begins to understand common words like 'no', 'by-bye' and knows mommy & daddy

• 9-12 Months

- imitates sounds you make
- will turn and find sound in any direction
 - vocalizes to get attention
- points or reaches for familiar objects



• 12-18 Months

- knows the names of family members
- enjoys music and may try to dance
 - imitates simple words
- follows simple spoken directions



• 18-24 months

- understands when you call from other room
- points to 2 or more body parts when asked
- uses jargon speech with intelligible words
- puts two or more word combinations together



PARENT TO PARENT



The majority of children who are identified with a hearing loss are born to hearing parents. In most cases there is no history of hearing loss in the family, and most know no other families in the same situation. This often leaves parents feeling very alone, and many find themselves searching out others who understand what they are going through. During this time parents find themselves being thrust into new and unfamiliar roles. They suddenly feel the need to become experts on the subject of hearing loss in order to make the right decisions for their child, as well as become advocates for the services their child needs immediately, and in the years to come. Initially, this task seems overwhelming for most parents.

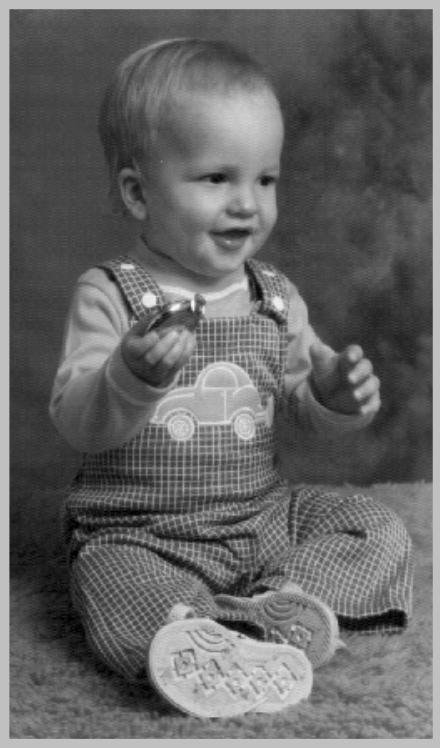
The goal of this section is to link parents to other parents who have walked in their shoes and have agreed to share their stories, experience, expertise, and advice. You will read how other parents reacted to the diagnosis of their child's hearing loss, as well as what they found helpful for coping during this time. You will also learn what they have found to be helpful to them when faced with some of the daily challenges of raising a child with a hearing loss. They will share their successes, as well as their fears, and will offer tips for working with professionals.



DUSTIN'S STORY

By Mary Reis

Every parent goes through a ritual of planning and dreaming when they receive the news that they are to become parents. Will their child become a lawyer, doctor, athlete, or ballerina? Whatever their dreams are, the wish of every parent is for a perfect and healthy child.



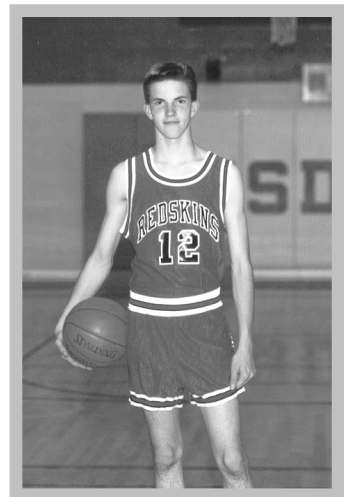
When our son was born, everything seemed perfect. He was a healthy, happy baby in every respect. He went through the terrible two's like every child, perhaps even more diligently than our other two children. He was always doing something mischievous, and each new trick made us wonder what his next would be. When he was three years old, my husband and I began to notice a few things in his habits and speech that didn't quite meet the expected norm. Many friends made the statement that he was just being a 'brat' by ignoring us. A neighbor, who was a speech therapist, suggested that we have his hearing tested. After having three different physicians and audiologists test and retest him, our son was diagnosed with a hearing loss. My husband and I thought our world had come to an end. Our hopes and dreams for our strong little boy were crushed.

At first we went through a denial phase, believing that the doctors had misdiagnosed his disorder. We knew something was wrong, but did not want to give up the

belief that it could be corrected. We continued looking for a doctor who would tell us that some form of treatment could repair his hearing.

There are many feelings that parents go through when something like this happens to them. First, there is shock...they can't believe that this is happening. Then, denial...they know the experts are wrong with their diagnosis, and continue seeking answers they want to hear. Guilt...parents often wonder what they did to cause the disability. Maybe during the pregnancy they did something that caused their child's hearing to be impaired, or perhaps, even wonder if God was punishing them for some unknown reason. Every parent has feelings similar to these. Frustration, depression, and even anger are normal feelings in this situation. Once parents work through these feelings and realize that they don't really have a DISABLED child, but a CHILD with a disability, their life will be rewarding and full.

When our son was first diagnosed with his hearing loss, we didn't know where to turn for help or how to find the available resources. This book is designed to help parents through that process. It is my hope that this book* can assist parents in finding the information they need and help them arrive at a point where they can look back and know they were blessed with a beautiful child



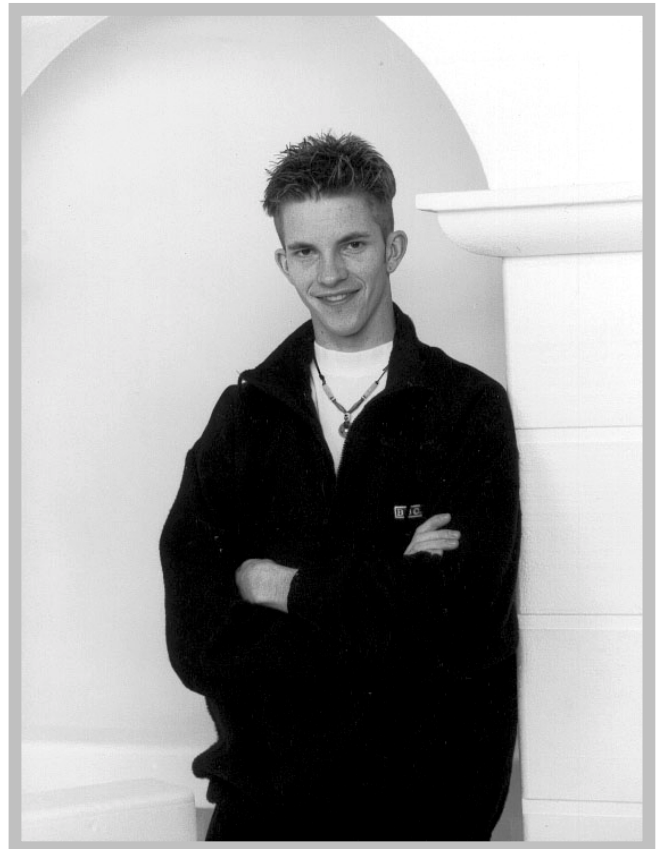


When our son was in grade school he won several gold medals for his writing skills in the Young Authors competitions. In high school, he not only competed but won awards in varsity football, soccer, basketball, baseball and track. He is an avid big game hunter and has been successful in his hunting career. He is now 23 years old and attending Western Oregon University. In June of 2003, Dustin will graduate from Western Oregon University with a Bachelor of Arts Degree in Interdisciplinary Studies with an emphasis in Business, Humanities, and Health /PE. He has traveled extensively and attended schools in California, New York, Washington D.C. and Oregon. He has driven across the U.S. in his own car and is a frequent flyer on the airlines. He is living a "normal" young adult life

and is not a DISABLED person by any stretch of the imagination....just a PERSON with a disability. We applaud him for his efforts and are very proud to say, "THAT'S OUR SON!"

This book is dedicated to Dustin, for without him we would not be where we are today.

Thanks, son!



*(*Excepted, and updated, from the original Help and Hope, written by Mary Reis and published in 1999 by the Council for the Deaf and Hard of Hearing.)*

SISTERS SHARE LOSS BUT NOT EXPERIENCE: LATE AND EARLY DIAGNOSIS OF HEARING LOSS



Being completely overwhelmed with the love we felt at her birth, and being totally unsuspecting, my husband and I had no idea our daughter, Corinne, had a severe hearing loss. We snuggled her close, counted her fingers and toes, and joyfully took her home. I took Corinne to all of her “well-baby” check ups. As she matured we began to sense something was not quite right. I expressed concern about the lack of developing speech or any attempts at mimicking to my pediatrician, who merely patted me on the back and encouraged me to count her vocalizations.

It wasn't until 22 months of age that Corinne was finally diagnosed with our nation's most commonly occurring birth defect, a severe hearing loss. She was quickly fitted with hearing aides. However, now at nearly two years old, she refused to let the aides stay in her ears. The late diagnosis greatly delayed early intervention services and critically damaged Corinne's expressive and receptive speech and language abilities for several years. We have spent hundreds of hours in speech therapy and communication coursework to overcome the damaging effects of delayed diagnosis.

Our Emily was born just six months after Corinne's diagnosis. An infant hearing test was performed and we were again overwhelmed to discover that Emily also had a moderate to severe hearing loss almost identical to Corinne's. Emily was aided at five months and immediately enrolled in an early intervention program. She accepted her aids and developed speech normally, right along with her hearing peers. Emily's early diagnosis prevented so many hours of work and worry.

Corinne is now age 10 and Emily is age 8. Our journey, though difficult and emotional at first, has smoothed out greatly. Corinne and Emily get great benefit from their hearing aids. Their speech is well developed and language abilities are at and above grade level. Our family has been greatly blessed by knowledgeable audiologists, patient speech therapists, and supportive extended family members who have learned Cued Speech. We have been tremendously supported by our parent school advisor and many other school leaders and teachers. We have witnessed many miracles as we learned to communicate together as a family. Although at times we continue to feel emotional about this process, we have found a wealth of love, and success. There is an immense amount of help and hope for your child with hearing loss.

By: Corrine and Emily's Parents, Boise, ID

For parent contacts within your region of the state, contact-- *Idaho Hands and Voices*
208-334-0829 or 800-433-1323



TREY'S STORY

by Trey's Parents, Idaho

On October 14, 1998, our son, Trey was born at St. Luke's Regional Medical Center in Boise, Idaho. Before we left the hospital we were told that Trey did not pass the newborn hearing test, one of the many tests he went through after birth. We were told not to worry that it could be fluid in the ears, but to schedule an appointment in one week for another screening test.

As the week went by, we began to worry about his lack of response to things like clapping loudly while he slept, or banging pots and pans. We talked about this with his pediatrician and waited for the next test. When he did not pass the second test at St. Luke's we were referred to Elks Audiology.

When we went to this appointment we had no idea what to expect. Kathleen Wachtler was our audiologist, the one who performed the auditory brainstem response test (ABR), and the one who told me that my two-week-old son could not hear me or anything else. This was devastating for our entire family.

Within two weeks we were in contact with the School for the Deaf and Blind (ISDB), and through our pediatrician we were also in contact with the Child Development Center (CDC). We were also recommended to have Trey fitted for hearing aids. By the time Trey was two months old, he had little tiny hearing aids. I remember people saying how cute Trey looked in his hearing aids. That was not what we thought when we first saw them. Having Trey wear hearing aids was sad for us, but we had some hope that he would be hearing our voices for the first time.

We were now learning about sign language, the Deaf culture and the Deaf community here in the Treasure Valley. Jill Muir, from ISDB, who came to our house every week, was so much more than a sign language teacher. She was a counselor in the emotional times, an educator when we had questions, our link to the Deaf community, and our friend.

After Trey had worn his hearing aids for one year, he still had no real response to sound and he had lost the sensitivity to real low sounds that he might have had when he was born. Kathleen suggested for us to start researching the cochlear implant. After several months of reading about the implant, talking to people with implants, and also talking to people who were opposed to implanting children, we finally decided to go ahead with testing to see if Trey qualified for an implant. He was approved and had the surgery on April 28th, 2000. His "hook-up" day was on June 16th, 2000.

Since Trey's "hook-up" day the process of learning to hear sounds has been slow, but very rewarding. This is not a cure for deafness and since this is a new procedure for Boise, there are not all the resources that are needed for implants. But, it is getting better all the time.

We still use sign language with Trey every day and he recently started pre-school for the deaf and hard of hearing. Trey does hear more than we ever expected, and is starting to make words with his sounds. We are excited for his future. He is smart, happy, and healthy. What else could we ask for?

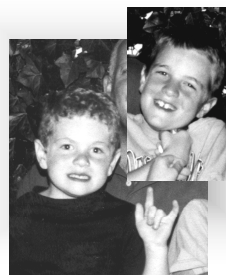
We want to say THANK YOU to everyone who has been a part of this journey of the last three years. We could not have made it as far as we have without others caring about our son and family.

We believe Trey and our whole family is a success because of early intervention and a strong community.

Help and Hope - 2003

JACOB & MICAH'S LADDER

As the mother of three sons, two of whom were born deaf, I wish that newborn hearing screenings could have been a routine part of their neonatal experience. My first-born son, who is profoundly deaf, was not diagnosed until age 21 months. All involved felt incredibly sheepish for missing such a profound loss for so long. As first time parents, we were in love with the idea of being parents. I was not at all alarmed by the fact that our son had never even turned to the sound of his own name. It was only too easy to believe the statements that were made by the ENT that our son would "catch up" in no time after tubes were in place.



After six months of waiting and watching for language to emerge, we asked for a second opinion about his hearing loss. The audiologist/speech pathologist requested an ABR for our boy. "Tomorrow would not be too soon", was her response. The ABR itself was exhausting! I didn't realize Jacob needed to be sleep deprived to have the test. We were emotionally paralyzed when we finally realized that Jacob would never "catch up". After fitting Jacob with the largest hearing aides I had ever seen, we were told to take him to a nearby state for an evaluation for Cochlear Implants. We traveled to Spokane and put Jacob through a series of tests, but it was impossible to get an accurate OAE reading for him. We learned months later that Jacob not only had a profound hearing loss, but he also received a diagnosis of severe autism. Thus began our travels up "Little Jacob's Ladder".

When we had Jacob tested for Autism, he scored more like a deaf-blind child on the assessments due to a lack of language exposure. We were told to expose him to a signing environment for a year and have him retested. After a full year of learning sign language, and taking him to programs that were signing, we were told to expose him for another year before a diagnosis could be made. **It took 2 ½ years to finally become eligible for services that would address Jacob's autism!** Had we known about Jacob's profound loss at birth, he could have had all the services he needed during his sponge-like language learning years.

Our second son, Micah was born in California in 1995. We had a deaf family physician at the time. He was acutely aware of the equipment available to screen the hearing of newborn babies, but to his dismay, it was difficult to locate the equipment and find someone who was comfortable conducting the screening. My suspicion of Micah's deafness was confirmed a very frazzling two weeks later. Our third child was born in California, in June of 1998. The same screening machine was still being used, but it was not something that many of the nurses had experience using. We did get a normal reading on our third child. We had also suspected that result as we now were looking for natural responses to sound.

As an early childhood interventionist, currently employed at the Idaho School for the Deaf and the Blind, I realize how precious those first years for Jacob could have been for language exposure. I can only wonder how much more language Jacob might have, had we not been delayed by not knowing how much hearing he didn't have at birth. There was no reason to single him out to screen him. He was not a high-risk baby. Could he have benefited from the added early information?... Emphatically.... YES! *My vote is for newborn hearing screening!!!*

By: Jacob and Micah's mother, Idaho

Help and Hope - 2003



RACHEL'S STORY

On May 25, 2000, our daughter, Rachel, was born at St. Luke's Regional Medical Center in Boise, Idaho. We are Rachel's parents. Like all parents expecting children, we were very excited.

Like her brother before her, Rachel did not pass her initial newborn hearing screening. We were not concerned, however, confident that fluid in her ears was the culprit. We simply needed to wait a few weeks and then Rachel would pass the test just as her brother did. We were impressed that technology such as Otoacoustic Emissions (OAE's) existed and could allow infants to have their hearing tested.

In June, Rachel's hearing was re-screened. The results were no better than the first attempts. A flurry of questions followed. "Is the computer working?" Is the software OK?" Are you sure you administered the test correctly?" Is it possible for the test to show false results?" What does it mean exactly if Rachel is not passing her newborn hearing screening?"

The news that Rachel failed her newborn hearing screening for the second time was a very big and unexpected disappointment. The possibility that Rachel might truly have something seriously wrong with her hearing was immensely unsettling. And the fact that further tests needed to be conducted before a diagnosis could be made added to Rachel's mom's anxiety and stress. Her dad was only mildly upset due to his firm belief that the problem was due to a computer hardware or software defect. Dad "proved" this by conducting his own hearing test. He fired a toy cap gun about six feet behind Rachel. She startled and he delightfully stated, "See, Rachel can hear."

One week later Rachel had an auditory brain stem response (ABR) evaluation (including bone conduction testing to rule out middle ear fluid) and a more comprehensive OAE test. The results of these new tests were consistent with the earlier screenings and confirmed that Rachel had hearing loss. We were both present for the diagnosis. We questioned the Audiologist on every facet of these tests and ultimately became convinced that there was a problem with Rachel's hearing. At this point we both had to face what we had been denying, Rachel was hearing impaired.

Rachel was diagnosed with severe bilateral sensorineural hearing loss. We were naturally upset, yet convinced we could fix whatever it was causing her hearing loss. Rachel's Pediatrician, Audiologist and ENT specialist all informed us that sensorineural hearing loss is not medically treatable. Because Rachel's problem involved nerves that were malfunctioning either due to damage or underdevelopment, her condition was essentially permanent, and could possibly get worse.

All of this news surrounding Rachel's condition and the implications for her and our family were numbing. Her hearing loss was as significant as the loss of a friend or family member. We needed to come to grips with her condition, identify treatment options, and move forward. Our goals were simple: she would speak intelligibly, attend regular school, and function in regular, mainstream society.

When Rachel was six weeks old, she was fitted with digital hearing aids; "Magic ears", as Bill calls them. We were greatly encouraged to learn that with her aids Rachel's hearing was much improved. We began to research various communication methods. Our efforts were centered on increasing the amount of time Rachel wore her aids and improving our proficiency in Cued English*.

The last 17 months have been a roller coaster ride. Her hearing has improved since her initial tests, and then recently began to decline slightly. Her ENT and Audiologist are unable to explain this. We believe everyone has a miracle in their lifetime, was this Rachel's?

Today, when we look at Rachel, she couldn't be more normal, healthy or happy. Rachel continues to be a beautiful, happy little girl who adores her big brother. We look to the future with great anticipation as to what she will achieve and accomplish.

* Cued English is one of many communication options available.

What We Have Learned...

by Rachel's parents, Idaho

- ♥ **The day of the diagnosis is overwhelming and filled with fear.** You can't imagine how you will raise your child and have the life you had dreamed about. You feel so much sadness for your child. We realized our daughter had never heard us say, "I love you" or "You are so beautiful."
- ♥ **It is actually a blessing to learn about hearing problems as a newborn.** The earlier the detection, the less impact the disability will have throughout your child's life.
- ♥ **Grieve the loss of your "normal/healthy" child** as you originally defined normal/healthy. Until you go through the grief process, you can't begin the healing process.
- ♥ **Don't worry about making decisions immediately.** The doctors and audiologist will guide you and let you know when you should be making some choices. Don't put more stress on yourself than necessary by feeling an intense need to make decisions in the first few days about things such as: what communication system is right, how do we mainstream our child in school, etc..
- ♥ **Enjoy your baby.** Don't let the setback of a hearing issue take the joy and celebration out of the new addition to your family.
- ♥ **Time heals.** Within two months we were surprised at how far we had come in accepting Rachel's condition.
- ♥ **Babies naturally attract a lot of public attention.** But babies with hearing aids attract a great deal more. In the beginning, the expressions of pity and sorrow for you and your child can conjure a number of emotions.
- ♥ **Never feel alone.** Resources of all types are available for whatever you need for your child. Our audiologist, ENT, pediatrician and case manager from the Idaho School for the Deaf and the Blind have been our most valuable resources. We have also met wonderful parents and families that continue to be inspirational to us.
- ♥ **Where is God in all of this? We believe He is everywhere.** He's with all the medical professionals that give so much of themselves. He's with the companies and employees who make hearing aids, teletype machines, fire alarms that flash lights. He's with the case managers and speech therapists that work so hard with the children and families. He's with the parents for having blessed them with such a beautiful child. ♥ ♥ ♥ ♥ ♥

COPING WITH THE DIAGNOSIS:

PARENT VIEWS

In this section, you will hear from other parents who have a child who is deaf or hard-of-hearing. They speak from experience. They have been where you are and understand what you are going through. Hopefully reading what they have to share with you will give you a sense that you are not alone...that your reactions are common...that things will get better.

For some parents acceptance of the hearing loss comes easily, while others may struggle with it for some time. For most, it is an ongoing process. In this section parents share their reactions to the diagnosis, coping strategies, and tips on how they dealt with the reactions of others.



COPING WITH THE DIAGNOSIS:

What Are Normal Reactions?

When we are told that our child is deaf or has a hearing loss, we normally experience a variety of emotions. These emotions may include relief, shock, fear, denial, sadness, grief, confusion, anger, guilt, disbelief, and surprise.



"When my daughter's hearing loss was finally diagnosed I felt such a sense of relief. That might sound odd, but I was so relieved because despite what her doctor and my friends and family had been telling me, I knew something was wrong. Finally getting a diagnosis meant that we had a place to start. We knew what we were dealing with, and now we could begin to educate ourselves and try to figure out the next step."

"I cannot remember anything they said after the word "deaf." I had to call the office later and ask for all the details over again."

"I was surprised to learn she had a hearing loss, and I felt guilty about the possible causes."

"I was very scared because it was unknown to us. We didn't know what DEAFNESS meant."

"I was very depressed for awhile."

"I was devastated and shocked. I remember only being able to go home. I wasn't able to get on with the normal daily activity. I just had to be at home. I was shattered. The first week I cried a lot, and desperately wanted to do everything in my power to make her hear! I had heard about the Cochlear Implant and my initial reaction was that it must be the way to make everything right again."

"I was relieved that it was ONLY deafness."

"For me, the hardest part at the beginning was fear of the unknown."

Uncomfortable Territory

Most of us have never had any experience with deafness or hearing loss of any kind, and therefore suddenly find ourselves launched into very unfamiliar and uncomfortable territory. For many, this experience is not unlike the grief process. It is very individual; everyone reacts differently.

No Wrong Way to React

Some parents have little problem accepting the diagnosis and seem to move on without a hitch, while others find themselves struggling to come to terms with it, sometimes for an extended period of time. Regardless of what your reaction is, be assured that it is normal. There is no right or wrong way to react.

ACCEPTING THE DIAGNOSIS

Just as individuals react differently to the news that their child is deaf or hard-of-hearing, acceptance of the diagnosis is also a very individual process.

"I find acceptance to be an ongoing thing. I have been able to accept that my daughter is deaf and I think I did that fairly soon after the diagnosis. It is something that never goes away because some new challenge always pops up to remind me all over again."

"I have a problem with the word acceptance. At what degree can you accept that your child has limitation in communication with other people?"

"After a short period, I accepted the hearing loss pretty well. During that time, I got every book on childhood hearing loss that I could find in the library. My goal was not that he will learn to read, but that he will not graduate with a lower reading level. I think the deafness was easier to accept for two reasons...we knew it was a very real possibility, due to the meningitis and that he was so sick that he almost did not survive. Given that, a deaf child is no big deal."

"At first I would wake up in the morning, and then I would suddenly remember. "Oh yeah, he's deaf, and I would feel sick. I still remember that feeling, although it did not last long."

An Ongoing Process

Most parents describe acceptance as an ongoing process, one that comes and goes over time. When talking about acceptance, we are not just talking about accepting the hearing loss itself. We are also talking about the acceptance that life as we knew it has changed. Initially it feels like everything has changed.

Over time, we become educated and realize that the hearing loss is merely a part of who our children are, not a definition of all they are. We knew how to communicate with our child, and suddenly that has all changed. We had a pretty good idea of where they might attend school and dreamt of the college they would attend and the career they might pursue. Now we have no idea how to even go about educating a deaf child or hard of hearing child, or even what options are available, let alone what the future might hold for them.

The Good News

The good news is that we do find acceptance and begin to adjust. Over time, dealing with a hearing loss just becomes a part of our family. It is still a part of our lives, but it is just that...a part of it. It is not the defining factor in our relationship with our child. It becomes comfortable and when we look at our child we no longer see the hearing loss, we see the child.

COPING STRATEGIES

Fear of the unknown is often worse than the reality of the hearing loss. Parents are often given the news that their child has a hearing loss, but are given little in the way of an explanation of what this really means.

"I needed to understand hearing loss and how the ear was damaged. It took me awhile to find out why it was damaged and where. That was an issue with me because I wanted to understand if someone, including myself, had made a mistake when he was sick with meningitis. I needed to know if something could have prevented his deafness."



"One of the most valuable things for us was to join a Parent Group. Being able to talk to those who really understood what we were going through helped tremendously. Even more important was being able to see deaf and hard of hearing children older than our own child. We were able to see just how normal they were, and it helped us to realize that she was going to be okay."

"I had no idea where to begin looking for the information I needed to understand my child's hearing loss. I began checking out every book I could find and presented it to the audiologist with a long list of questions every time I saw him. I wanted to know what she heard, what hearing aids would do to help her, what options we had for communicating with her, etc."

"We were in the mall and I saw two deaf people signing. I knew no signs and had no idea how I was going to communicate with them. I just knew that I had to connect with someone who understood deafness. Prior to my child's diagnosis I would never have done anything like this, but it is amazing what you will do when you are starved for information and don't know where to find it."

"Getting involved with other parents was a life saver. Our family and friends were supportive, but they didn't really understand what it was like for us. Being with other families who had a child with a hearing loss helped us relax and find the comfort and understanding that we needed as we struggled to figure out what to do for our child. In this group, hearing loss was normal, not something to be pitied or feared."

Making Sense of the Unfamiliar

For most parents, finding out all we can about our child's hearing loss and what it will mean in terms of language acquisition, communication, family dynamics, education, and social development is the key to coping.

As we take our child from appointment to appointment, we are bombarded with unfamiliar technical and medical terms. We know we need to be asking the right questions, but don't even know what those questions are.

To make sense of it all, many of us turn to libraries, the World Wide Web, or phone books to find agencies that serve the deaf and hard of hearing. Some of us even walk up to complete strangers who are wearing a hearing aid or signing. This quest to educate ourselves, is something all parents with a child who is deaf or hard of hearing have in common.

Information On Deaf Culture and Community

Soon after being told that our child is deaf, many of us are told that there is something called "Deaf Culture," or "Deaf Community." The idea of our child becoming part of a culture or community that is foreign to us may be frightening. Understanding what is meant by these terms can be very helpful. We discover that there is a rich culture that our child may someday choose to be a part of. It is nothing to be feared.

Deaf and hard of hearing adults can be a wonderful source of information and education, as well as provide support in raising our children. Most are willing to share their knowledge and personal experiences with us, and welcome questions from parents who are striving to make the best decisions possible for their children. You will find links to web sites and contact information that will connect you to these individuals in the resources section.

DEALING WITH THE REACTION OF OTHERS

In the midst of having to accept and come to terms with our child's hearing loss, we are also in the position of having to deal with the reaction of family and friends, and sometimes the community we live in. Just as each of us react differently, there is no way to predict how those closest to us will react.

"Our family cried. People were sad, and to an extent, annoying. Many would clap their hands and do their own "hearing tests" or give unwanted advice."

"My family has always been close by and we have always been close. They supported us emotionally."

"The biggest mistake I made with my family was to cry all of my tears before I called them to give them the news. I knew my parents would be upset by the news, so I wanted to protect them by acting as if everything was fine. Because I was so in control and seemed to be handling it so well, they assumed that I was fine. If I had been honest with them and let them know how devastated I was, they would have been much more able to support me when I really needed it."

"People were mostly sympathetic toward us. Most people didn't offer too much, but those who "knew someone who knew someone" put us in touch with a few other parents of children with a hearing loss."

"Many people announced that they would learn to sign, but no one really did."

"My parents were very supportive and understanding. My mom said, "So we have a special little girl." That was precious. Many of our friends and family, including my brothers and a good friend, made an effort to communicate with our daughter. However, others really didn't understand what we were going through, how to help, or how to react."

How Grandparents React

An important thing to remember with Grandparents is that not only are they sad for your child, they are sad for you as well. Just as we want to make everything right for our children, they want to do the same for us. They feel helpless and often go through their own time of grieving.



While most want to be able to support you through this time, realize that they themselves may be having a difficult time of accepting the news that their precious grandchild has a hearing loss. Seeing your child wearing a hearing aid or the thought of trying to learn a new language to communicate with their grandchild (if sign language is the chosen method of communication) may be very difficult for them. Just as you need time to adjust and adapt to the changes in your life, they too need time.

HOW DO WE DECIDE?

Throughout this section, you will read about the experiences of other parents who have made important decisions for their deaf or hard of hearing children. These parents discuss what they have found to be the most helpful when having to make difficult decisions, and talk candidly about how they have dealt with others who have disagreed with their decisions.



Where Do We Start?

Making decisions for our children is difficult enough when they do not have a hearing loss. When a disability is thrown into the mix, making decisions becomes much more complicated.

At the time of diagnosis, most parents know little about hearing loss and the implications for their child. In fact, most of us are acutely aware of how little information we have to base our decisions upon. Sorting out what decisions need to be made immediately and which ones can wait is often difficult. Parents are put in the position of having to rely on others, primarily professionals, to help them make these decisions.

While professionals are most often knowledgeable and helpful, parents can benefit greatly from practical information from other parents. It is important for parents to know what their rights are, and to be presented with all of the options available before making a decision.

Parents also need to understand the importance of being flexible and realize that no decision is set in stone. Just as all children are different, no one mode of communication or educational placement is right for every child. Understanding this helps parents realize that changes may need to be made along the way, and that although they will not always know for certain that they have made the right decision at the time, there are other options that can be explored if need be.

Before we even have time to adjust to the idea that our child has a hearing loss, we find that there are many decisions to be made. We are often asked to make important decisions while still feeling very overwhelmed, and often have no idea what might be best for our child. It is important to remember that we make decisions based on the information we have at the time, and that most decisions do not need to be made immediately.

~"For us it helped to ask whether or not a particular decision had to be made immediately, and if so, why. More often than not, when we explained that we were unsure of what to do and that we felt like we needed a little more time to decide, professionals would tell us that it was not harmful to wait until we were sure. Knowing that we were having a hard time making a decision often prompted them to help us find more information or other individuals to talk to about our concerns."

~"When you feel overwhelmed with decisions, try to get all the information you can from as many sources as you can. Trust your ability to decide based on that information. Have faith in your knowledge of your child. Indecision is so much more difficult than deciding on something and moving in a positive direction."

~"Don't make any decision if you are being pressured by someone else to do so."

~"We are so much more fortunate now than parents as recently as 20 years ago in the fact that there are so many more resources available to us. However, throwing all those resources into the mix can make it even more confusing. Don't listen to just one person."

To make really good decisions you must know all the options. Reading about these options and doing research is a fantastic way to start. More importantly, seek out other parents who have gone through the same thing. It may also help to talk to various deaf and hard of hearing adults and get feedback on the choices their parents made for them

~"Take time to grieve and really come to terms with your child's hearing loss, and don't make decisions based on emotions. Listen to the advice of various people with different views...your doctors, specialists, therapists, teachers, educators, other parents. Read, get onto the Internet and do some of your own investigating. Educate yourself and get a good understanding of the options that are available for your child. Put it all together and think about it rationally so that you can make the best decision for your child based on what you think and feel, and from the information you have gathered and filtered through."

The Key to Making Good Decisions

The key to making good decisions for your child is knowing all of the options that are available, educating ourselves about those options, and not being pressured into making a decision until we have enough information to feel comfortable to do so.

~"Before making decisions for your child, be sure to get all of the information you can from reliable sources. Make the decision based on the best information you can get at the time, and don't look back."

~"The key to making good decisions is information. Get this information from books, from other parents, from deaf adults, from wherever you can get it."

~"For us, the key was always taking the time to educate ourselves. Sometimes that meant not making a decision right away. Most of the time an extra day or two will not make a difference, and to make a good decision you often need a little more time to do the research and feel good about the decision you make."

~"Ask experts around you questions and become informed. Play an active role in your child's education. Don't be afraid to push for what you believe is best for your child."

~"Knowing all of your options and talking with as many people as possible that have chosen different things and seeing what their outcomes were is key to making good decisions."

~"Some of the keys for making good decisions are education, loving concern, and prayer for wisdom! Don't be left in the dark about your child's condition, and don't assume that your child is exactly like another child with the same disability."

Where Do We Find the Information We Need to Make a Good Decision?

Most parents would agree that the best way to make good decisions for their child is to be educated and well informed. Not knowing where to find the information you need can be very frustrating. Professionals can often be a good source of information, but many parents feel the need to do their own research in order to feel comfortable about making a decision.

~"We often found that our best resource was other parents who had been in a similar situation. A parent's first loyalty is to their child, not a school district or their employer. Most often their only concern is the welfare of their child, and they are more than willing to be open and honest with you about their own experiences. Also, they will often be able to refer you on to other parents who might have more experience, or point you to reference materials that they used when trying to make a specific decision for their own child. They have seen first hand many of the pros and cons surrounding a specific decision they have made in the past and are usually very willing to share this information with you."

~"Talking with other parents and our parent advocates and service coordinators has been the most helpful. Also, talking to deaf adults and younger deaf adults about their experiences has been helpful."

~"Besides taking part in various activities involving other deaf and hard of hearing children and their families, and working closely with our child's teachers and caregivers, we have found that there are various sites on the Internet where you can communicate with deaf or hard of hearing persons, or other parents, and gain from their wealth of experience."

~"Fortunately, because I am deaf, I already knew many resources when I found out that my daughter was deaf. However, that did not mean that my choices and/or decisions came about easily. I have had many battles with school districts and other parents. State Commissions for the Deaf and Hard of Hearing are excellent resources and have offered me assistance in many different ways."

~"One of the first things I have always done is to talk to parents with older children who have been in a similar situation. Often they have already done the research in order to make a decision, and are able to share that with you, as well as being able to share the results of that decision. The thing to remember about doing this is that every child is different. So what they decided may not necessarily be the right decision for your child."

~"I get my information from...wherever I can find it. Ultimately it is just you!"

When Others Disagree With Our Decision

At times, parents are confronted with opposition when having to make a difficult decision for their child. There are always those who will disagree with the mode of communication we select, the educational placement we choose, or whether or not our child should wear hearing aids or get a cochlear implant. Often those who disagree with us can be very intimidating.

One very important thing to remember is as parents, it is our right and responsibility to make decisions for our children until they are old enough to make them on their own, regardless of whether or not they have a hearing loss. We make decisions every day for our children. And, even though we may not always know for certain that a decision we are making for our deaf or hard of hearing child is the right one at the time, it is our job to do what we think is best for our child, based on the information available to us. Knowing how other parents have dealt with opposition can be very helpful.

~"When it comes to the education of a child with a hearing loss, everyone has an opinion. When I was met with opposition about our choice of communication mode or educational placement for our daughter, I tried not to let myself get drawn into the argument of which was the 'right' one, or the 'better' one. Instead, I merely stated that we felt that this particular choice was best for our child. I made it a point to tell them that I didn't think that their opinion was necessarily wrong, but that right now we felt that the choice we'd made was the best, or most appropriate one for our child. Those who voice their opposition the loudest are usually not going to be swayed anyway, so it is futile to get into an argument with them. I've found it much more productive to change the subject to a more neutral topic. If that doesn't work, then find a way to excuse yourself from the conversation. I decided early on that I had no obligation to justify my decisions to those who do not have a personal stake in my child's life."



~"Don't apologize for the decisions you make for your child. It is your right as a parent to make decisions for your child."

~"We faced disagreements over choosing SEE II over ASL. We informed ourselves, considered our goal of English proficiency for our child, our family's needs, and simply stuck to our conviction. If you face opposition from educators, it is always best to bring an outside party to your Individualized Education Plan (IEP). Never go in there alone, and tape record the meeting if necessary. People will be much more wary of what they say, if it is being taped."

~"That feeling is awful, and I have been made to feel that I am disrespecting the Deaf community. But, how can I be disrespecting them if I am trying to do what I think is best for my child? I think this is the key...to be able to say I am doing what I think is best for my child, and for our family situation. What may be best for someone else may not be best for our family. It is easier said than done, but you have to be strong enough to make the choices based on what best fits the needs of your family."

~"Tough as it is at times, when we are faced with disapproval of the choices that we have made for our children, we must not be intimidated by the opinions of others. It is of the utmost importance that you believe in the choice that you have made, and that you stand firm in it. Let people know that this is the decision you have made, and that you firmly believe it is the best one for your child. They are entitled to their opinion, but remember that it is just an opinion. You can see for yourself the progress and success that your decisions have brought about for your child. There is no harm in listening to what other people have to say, and gathering information that might help give you another perspective, but don't be swayed just because they are opinionated. Make sure that what you receive from others and apply is good for your child and for you."

~"This is a tough one. Some days it is so hard to be an educator about deafness. I just want to buy my groceries and go home. I just want to enjoy watching my son play baseball. I don't want to explain why we use sign language, or why he doesn't have a cochlear implant. I think the hardest time for me is when my family questions some decision I've made. While they are my family, they don't understand deafness to the depths that I have learned it, lived it, and experienced it. Another tough one is when a deaf adult questions something. That is very intimidating. They've really lived it, while I'm living it through my son. The best advice I can give is to smile and nod at the person who questions you and then go home and call your best friend or someone who will listen and support you, encourage and empower you. Then take a hot bath..."

~"When faced with opposition, try to listen to what the person's opinions are. But remember that not every child is the same. If it becomes more than you can take, distance yourself from that individual. Find another parent who may have a more open mind to the direction you are taking."

~"The best thing we've found is to not let yourselves get caught seemingly ignorant of the options open to us. This takes research and study, which of course is hard for busy parents, but when friends, relatives and well meaning others see that you are at least checking into these things, they are less likely to try to push you into making a decision or accuse you of being indecisive. The best answer we've found to give is, 'We just don't want to make a rush decision at this time, and we will make a decision as soon as we have checked into all the different views on the subject.'"

What If We Make a Decision That Turns Out To Be the Wrong One?



We have all experienced making a decision for our child that we thought was the right one at the time, but later discovered that it might not have been the best choice after all. Unfortunately, that is a part of life for all of us. None of us is going to make the right decision every time. Fortunately, most decisions are not a matter of life or death, and we have the opportunity to re-evaluate the situation and look at other options.

Being flexible and open to other options is a critical part of raising a child with a hearing loss. When something isn't working for our children, we need to be able to admit it, search out advice from others and change directions in order to find a better solution. We also need to be able to forgive ourselves and accept that we made the best decision we could with the information that was available to us. We then need to move on and not look back.

~"I have learned over the years that you cannot go back and kick yourself for the decisions you made years ago. If you have done your research and feel that you are making the best decision at the time, you cannot second-guess yourself. You make your decisions based on the information you have at the time, and none of us make the right decision 100% of the time."

~"Know that there is no right way for everyone. No one knows what the best thing is for your child, you just have to watch and look for signs that a certain method is not working and be willing to try other ways."

~"We all have to make decisions, and sometimes it's hard to know which is the right one. But you did the right thing...you made a decision. If it didn't work, well fine, you learned from it. You have a better understanding of the goal that you want to achieve, and you make the necessary changes. Don't be disheartened that you made a mistake. What counts is that you made the decision. It may be hard to work to change that decision, but you can do it, and your child will benefit from it."

~"I used to joke with parents of older deaf children, 'Why isn't everything laid out for us? Why aren't all the big decisions obvious, due to other people's experiences? Why isn't there a plan that I can easily see will work for my child? Why are we still fighting battles?' The answer is that there are no clear-cut answers. Every child is an individual. Every child who has a hearing loss is different. Remember that life is about learning from our mistakes. Your child isn't the mistake. Of course it is difficult when you are in the middle of a 'learning experience,' and you're feeling guilty about making a decision and then re-deciding that it wasn't the best choice. We can drive ourselves crazy trying to find the right answer! If you simplify a 'wrong' decision to mean you lost time, your child missed an opportunity, your child missed out, then hey, it could have been worse. We are human, after all."

More Advice from Parents



The best thing about getting advice from others is that we can choose what we want to do with it. We can take it, we can ignore it, or we can put it on the shelf for later.

~"When facing a decision, have a goal and then take each step as it comes. It can be overwhelming trying to make so many decisions for your deaf or hard of hearing child. Be prepared to change your decision if it is wrong, but don't change it every time you hit an obstacle. Make a change only when you are really sure that the choice you made initially was wrong, and that there is a better option for your child."

~"It has been my experience that many parents (myself included) often take professional's advice as gospel. While there are many wonderful professionals out there working in the field of deafness, there are also many who have very, very little knowledge of deafness, and they are advising parents on important issues. Make sure the professionals you deal with are knowledgeable on deafness because deafness is much, much more than the inability to hear."

~"Parents have to keep in mind that they need to be very careful not to make a decision based on what is best or easiest for them. All too often I have seen parents go for the oral method and think the child is a success because they can utter a few words. However, to others it is obvious that the child is miserable and secluded. Speech isn't everything. There are many who can be successful with the oral method, and there are many who can't. Watch, listen...talk to your child."

~"Decisions must be made with an objective in mind. Ask yourself these questions before you make a decision: 1) What do you want your child to achieve? 2) What are your goals? 3) What are the needs for equal access and accommodation? 4) What would you do if your child could hear? These are all good things to consider when thinking about a question or concern."

~"I really think the key here is communication. Regardless of the method or mode, it is imperative that parents are able to communicate with their deaf or hard of hearing child. Parents who have limited communication with their child will not be able to effectively determine how the child is doing socially, emotionally, and educationally. I also feel that exposing your child to as many methods, modes, etc. as possible gives the child the opportunity to naturally lean towards what's right for them. They are not old enough to make a 'conscious' decision, but you can observe and see which way they lean. I placed my daughter in the local residential school for preschool. They used Total Communication, so she was exposed to both sign and voice. I let her show me what worked for her. She remained and is still very much oral. Today she is fluent in both Total Communication and ASL. I feel good about having let her show me."

WORKING WITH PROFESSIONALS



Parents who have received the news that their child has a hearing loss often report that the health professional who broke the news was not as sensitive to their situation as they would have liked. In this section, parents will learn how to get the most information from professionals, how important it is to become a part of their child's care team, and much more.

BREAKING THE NEWS TO PARENTS



Often the very first information parents receive from a professional is information that may rock their world. How this information is presented and interpreted often sets the stage for all future interactions between the parent and the professionals who will serve their child for many years to come.

"I think everyone was very cautious in what they told me. One day I was talking with a woman on the phone and I must have been totally clueless. She said, "Hannah is deaf...I mean deaf." That was the first time I heard that term! I appreciated the cautiousness, but I especially appreciated the boldness of that woman."

"We were told by the audiologist in a very professional and caring environment. She cried with us!!"

"While the ABR was being done the technician talked to her assistant about my daughter as if she was a research subject. When they finished, they told me the results in very technical terms that were foreign to me. After about five minutes I stopped them and asked if this meant that my child could not hear, and they looked at me like they couldn't believe I'd even asked that question. I left not understanding the results. Fortunately, my daughter's Pediatrician cared enough to call me that afternoon after he received the results. He explained everything clearly, asked how I was doing, and told me what we needed to do next."

"After using some noisy toys, the Ear, Nose and Throat specialist told us that our daughter had a profound hearing loss. He was mildly sympathetic, but offered little in the way of further assistance. He simply made the diagnosis and that was it. We had to go home and deal with the rest ourselves."

Receiving the News

Hopefully when you received the diagnosis, you were told in a sensitive, supportive manner. Perhaps the professionals helped you understand what to do next. As you can see from some of the quotes above, not all parents have a positive experience. In an effort to convey information accurately to parents, professionals sometimes forget that they are dealing with parents who may be receiving devastating news, or at least news that they were not prepared to hear.



Making a Difference for Parents Who Follow

Most professionals strive to provide the best possible services for our children, and input from parents can be very helpful to them. Letting them know how this affected you, and suggestions on how they might better present information to parents may well make a difference to parents who follow you. If yours was not a positive one, you have the chance to turn a negative experience into an opportunity to educate the professional.

BECOMING PART OF THE TEAM

You are not "just a parent," you are one of the professionals. You are a key player on the team

"I want professionals to understand that there is so much more to my daughter than her hearing loss. She is not just an audiogram. She is not just a test score. She is a child who just happens to have a hearing loss."

"When professionals acknowledge that the parent knows the child in a way they never will, they can tap into the best resource possible."

"I think that sometimes professionals see things and automatically put us in a category without even getting to know us. Without even realizing it, they are putting stress on our families that doesn't need to be there. Each of us is an individual, each of us handle things in different ways. For some of us, a child with a hearing loss is a breeze. For others it is a struggle. We all have challenges in different areas, and too many times professionals don't take the time to find out who we are and who our children are. We aren't the families of previous years and the dynamics of our children and families are different, so our needs are different."

"We know our child best...Listen to us. Help us achieve our goals. Think of us as a team."

"I want professionals to know that despite my daughter's multiple disabilities and developmental delays, she is capable of doing many things, with good potential for the future."

A New Role for Parents

Immediately after the diagnosis, a flurry of activity thrusts parents into new roles that are unfamiliar and sometimes intimidating. Until now we knew our child so well, and we were the center of their universe. Often, overnight we find ourselves in the position of having to trust a number of professionals who seem to know more about our child than we do.

You Know Your Child Best

One very important thing to remember during this time is that while you may not understand the hearing loss and all that goes with it, you still know and understand your child better than anyone else in this world. What sets us apart from the professionals is our emotional attachment to our children. While this attachment can sometimes get in the way when we are working with professionals, it is also the force that drives us to settle for nothing but the best and go to any length to figure out what that may be.



DEVELOPING THE RIGHT ATTITUDE

Go in with a positive attitude. Veteran parents will tell you that your attitude often sets the stage for how professionals perceive you and interact with you. Don't walk in with guns blazing, but go in expecting the best. You will have enough battles to fight in the years to come without having to look for them. Learn to be assertive when you need to be, but don't walk through the door expecting a fight.

"As my daughter grew and professionals got to know me better, a mutual respect developed. At first I found that I had to be much more assertive. As time went on, we developed a comfortable working relationship and began to work much better as a team."



"Over the years my wife and I have learned so many new things about raising children and education for deaf children. However, we would not have learned what we have unless we were willing to admit that we didn't have all the answers. We are so very thankful for the doctors, professionals, teachers, sign language instructor, etc. who took the time to explain everything."

"Parents must share information with professionals to help them understand their children better, but parents must also listen and learn along the way."

"I learned that it is not always a bad thing to be wrong. As a parent, we have to go with our gut instinct. Many times our instincts are right, but sometimes they aren't. When that happens we need to be willing to admit it and change directions."

LEARNING TO BECOME AN ADVOCATE FOR YOUR CHILD

Learning to become an advocate for our children is one of the most important actions we can take to help them with their hearing loss.

"As I learned more, I became more assertive and learned how to be a better advocate for my child. I learned not to be intimidated by professionals, especially those who had a lot of book knowledge, but knew nothing about my child personally."

"Over time we have learned to be more aggressive and proactive with health professionals, and we refuse to be made to feel ignorant or incapable just because we don't know the medical terms."

"I realize now that if I want to do things a certain way, I have to say so. If I want to know something, I have to ask. I am my child's advocate and must act as such."

"I understand things better now. I'm not hesitant to ask questions, I have expectations. I try to work as part of a team."

"We went from knowing nothing about premature infants and hospital procedures and hearing loss, to the point where now we want to understand everything the doctors and specialists are sharing with us.."

"I no longer feel like the ignorant one who is ready to jump at whatever advice the professionals offer. I have learned that there are many opinions, and that many professionals lack a certain understanding that parents have, simply because the child is their own. I have learned to stand up for my opinions and beliefs and the things that I know to be true in my daughter's life, and not let the opinions of professionals undermine me."



Standing in the Gap Between Child and Professional

Very quickly, most of us come to understand that we are the ones who will be standing in the gap between our child and the professionals. Because we love our children and want the best possible services for them, this is not something we have to think about doing, we just do it.

Welcomed Input

Fortunately, many professionals welcome input from parents and are grateful to be able to work with an involved parent to figure out what is best for the child. The hard part comes when we are faced with having to challenge the opinion or advice of a professional. It can be very intimidating to walk into a room full of professionals. An important thing to remember is that you are part of the team and you deserve the respect and consideration of those working with your child.

LEARNING FROM THOSE WHO HAVE BEEN THERE BEFORE YOU

None of us becomes an advocate overnight. We learn to do this as the need arises. It takes time and effort to reach the point where you are confident enough to walk into a room full of professionals and go head to head with someone who is more educated on the subject than you are. Tapping into the knowledge and experience of "veteran parents" can be an excellent way to learn to advocate effectively for your child. Most are more than willing to share what they have learned over the years.

"I discovered early on that one of the best resources for learning how to work with professionals were the parents who had been doing it for years. From them I learned what my rights were, as well as more tactful ways of stating my opinions and making my requests known."

"Many new parents feel bewildered when working with professionals, as usually they know little or nothing compared to the years of study and practice of those working with their child. They need to not be afraid to say they don't understand, or to ask questions, or for suggestions on reading materials that they can read up on to help them understand the situation better."

"Don't be afraid to ask questions if you don't understand. If the professional acts impatient or otherwise makes you feel uncomfortable or stupid, find someone else!"

LEARNING HOW TO DEAL WITH YOUR CHILD'S HEARING LOSS

It is normal to feel a sense of urgency to learn everything you can immediately. While this is an admirable goal, it is not always a realistic one. Most of us have many other things that demand our time and energy, including a spouse, other children, a career, etc.



"In the beginning I did not like being an "advocate." Now I know that being an advocate was the best thing I could have done because I was able to teach my daughter to do it for herself when she got older."

"No one knows or understands a child like his or her parents. The fact that your child is deaf or hard of hearing does not give professionals the right to believe that their opinion or understanding is better than yours. Each child is unique, and only the parent has that built-in sense of knowing where that child is."

Permission to 'Just be a Parent'

Begin to do everything you can to educate yourself, but also give yourself permission to 'just be a parent.' It is easy to get lost in the learning and forget to slow down and enjoy your child. The more time you spend with your child, the more you come to know and understand them, and remember that THIS is what makes you such an important part of the team...you know your child better than anyone else!

Educating Yourself

Educating yourself is key to learning to work with professionals effectively. This education may come in the form of:

- Learning everything you can about your child's hearing loss
- Talking to other parents who have been in the same situations as you are in
- Learning about what services are required to be provided for your child
- Finding out what rights you have as a parent when decisions need to be made concerning your child

Preparing Yourself

It would be nice to think that we could quickly and easily learn everything we need to know before we need to know it. Unfortunately that is not usually the case. There are, however, a number of ways to prepare yourself:

1. **Prioritize** - There is so much to learn, so it is often helpful to prioritize the information you feel you need to know. Breaking it down makes it less overwhelming and easier to deal with.
2. **Identify Resources** - Many resources exist that can help you understand your child's hearing loss, including:
 - *Other Parents* - Very often veteran parents are eager to share their experience with new parents. Ask the professionals working with your child to put you in contact with other parents.
 - *The Internet* - Conduct searches that specifically look for information on hearing loss, amplification options, choices in communication and education, etc.
 - *Local Agencies* - Contact local agencies specializing in services for the deaf and hard of hearing. They often have access to classes and public service information that they can share with you.
 - *Your Local Library* - The library is filled with information that can help you understand your child's hearing loss, including books, periodicals, access to the World Wide Web, newspaper clippings, and more.

Please refer to the Resources Section to find information about these and other resources.

3. **Keep Good Notes** - As you find the information you need, print out hard copies, take notes, etc. Many parents find it very helpful to keep a journal or write notes as they think of questions or concerns that they want to address with the professionals who work with their child. It is often hard to digest everything at once, and this allows you to go back and review information when you have some time to yourself. Information that is particularly helpful and good to keep for future use is information on the IFSP (Individual Family Service Plan) and the IEP (Individual Education Plan) process.
4. **Ask Questions** - Ask questions and keep asking until you are satisfied that you have gotten the information you need. If your Pediatrician, ENT or Audiologist does not have the answers, ask to be referred to someone who does. Most are very willing to help you find the answers you need, but often do not do so automatically without you requesting it.

PARENT TALK

Parenting can be both joyful and challenging, even in the best of circumstances. When an infant is born with a hearing loss many parents face uncertain family issues. Often they are unsure who to turn to for guidance. One of the best sources of advice is other parents who have already dealt with some of the same issues.

In this section several parents of deaf or hard of hearing children



talk about how they approach specific situations, including getting the entire family involved in a supportive manner.

RAISING A CHILD WITH A HEARING LOSS

- Is raising a deaf or hard of hearing child any different from raising a hearing child?

~ "For us, the biggest difference in raising a deaf or hard of hearing child (ours is our 11th child!) is that it requires much more love and patience on the part of everyone involved. Parents, siblings, and relatives have to get down on the level of this child and put themselves in his shoes and not always expect quick results. The little one needs a lot of encouragement and reassurance with hugs, squeezes, and fun time together, or they can tend to feel left out of our hearing world."



~ "One of the best pieces of advice we ever received came from the family counselor assigned to us shortly after our daughter's deafness was diagnosed. She looked at us and said, 'Your child is the same child she was before you found out that she has a hearing loss. The only difference now is that you may have to learn to communicate with her a little differently.' This helped set the stage for our attitudes and opinions about what our child would be capable of, and because of this, our expectations for her have always been the same as they have been for our hearing child. We saw no reason to ever expect less of her, or assume that she would or could achieve any less than our son."

~ "Having a child who is deaf or hard of hearing will take more on your part as a parent. More time, more patience, and more work. It will be different from a hearing child. Different isn't bad, it's just different! Each child is unique and has a variety of needs. The demands of extra time could just as easily come from a child with a learning disability, or an extremely bright child. It doesn't in any way change or diminish all of the wonderful experiences of being a parent. Some of them might be different, but different is a good thing!"

~ "Yes, there is a difference. It takes more patience and time to explain things and fill in the missing pieces from the lack of incidental learning from 'overhearing.'"

~ "Raising a child with a hearing loss is different from raising a hearing child. Parents must become informed about the challenges hard of hearing children face in education as well as socially in order to encourage the child and intervene when it is necessary. For the hard of hearing child's benefit, it is important to raise him as much like a hearing child as possible in order to facilitate future success in life."



~ "It is very different! Communication is constantly an effort. Even if you know all the signs (if you are using manual communication), you still have to make sure that you have your child's visual attention, and that they get your attention. You are always looking up from what you are doing, always dropping things to get your hands free! It requires a lot of explaining and extra work to keep up with their hearing peers. Every day is a constant challenge."

~ "Somewhat. You have to intercede on their behalf more, because their 'disability' isn't obvious. You have to be more deliberate in your communication."

~ "At first there seemed to be a very big difference, mostly because of communication issues. Once we had established communication with our daughter and could explain things more easily and could understand what she wanted or needed, there were very few differences in how we interacted with our children."

~ "Same love, same expectations, same relationship. The only difference is in the language and the need to have your child look at you, and your need to have your hands free if you sign."

~ "The biggest difference I have found is that if your child is deaf, everything has to be deliberately taught. Nothing is picked up through osmosis. They do not automatically pick things up from conversations around them, or from the radio or television like our hearing children do. Even though we have good communication in our family, when my daughter was in high school I really started to see how many little incidental things she had not picked up on that we take for granted, because our hearing children do it so naturally. I suddenly found myself feeling very panicky, thinking about all I still had to teach her before she graduated from high school. The things that I realized she had missed out on were not so much the really big important things, but the small things in everyday life that we don't even think about. They were the things that would not necessarily make a difference in her life in the big scheme of things, but things that my hearing child knew, just because he could hear."

-Are your expectations for your deaf or hard of hearing child any different from those for your hearing children

~ "The interesting thing about expectations is that they change. They change for all of us as we grow, find new interests, and meet new people. It is often said that parent's expectations and dreams for a child change once they discover that the child has a hearing loss. This may be true, but don't our expectations for our hearing children often change as well once we begin to see the child's personality take shape and discover who they really are as they grow? It is the same with our children who have a hearing loss. No one can predict when a child is very young what kind of person they will become, or what they will do



with their life as an adult. Many of the dreams and expectations we have for any of our children may not be realistic for that particular child. Even if they are, our children may have no interest whatsoever in becoming who we envision them to be. It is up to each of us to choose our own path as we approach adulthood, and more often than not, the expectations and dreams that parents have for a child are far different from what the child may choose. When speaking of expectations, we need to focus on helping the child reach their fullest potential.

~ "Maybe a little. Speaking of the school age years, grade-wise and school performance-wise, we expected excellence to the best of their abilities. Realistically we understood that in some areas, such as standardized tests, there might be a lower performance. Behavior-wise, no difference."

~ "No. Whether hearing or not, I expect my children to do their best in school, treat others with respect, and become useful individuals in society. Kids live up to your expectations."

~ "I have always had the belief that aside from the obvious, like being a receptionist or dealing with telephone conversations, my daughter who is deaf will be able to achieve as much as my hearing son or any other hearing child, and that she will be a successful adult. The reality is that it will always be more difficult for her to achieve what she wants to or needs to do in school, or in the work place. I make allowances for that which she has not quickly understood. I also make allowances for the communication issue, but I seldom think of her as being any different from the other children. When I think of her, I think of her growing up and doing things just the way I did or any one else would. She is my daughter, and she is a person with a future. She just happens to have a hearing loss."



~ "No, my kids are both bright, social children, and I see no reason to have different expectations."

~ "Yes and no. Behavior expectations are basically the same. Expectations for other things, such as sports or employment may be different because it requires more time and explaining."

~ "My deaf child has a mild form of cerebral palsy, so as far as ambulation goes, that is different, but not in anything else."

~ "We set goals, expecting him to continue to improve in all areas, but we also follow his lead."

~ "My son can be whatever he wants to be. My expectations are certainly that he will go to college, but what career he decides to pursue is up to him."

DISCIPLINING A CHILD WITH A HEARING LOSS

- Do you discipline your deaf or hard of hearing child any differently than your hearing child? If so, in what way?

~ "I don't think we discipline our deaf child any differently. Perhaps when he was very young he might have gotten away with something because of lack of understanding of what we expected, but that didn't last long."

~ "No. We expected honesty, self discipline and obedience from both of our children."

~ "I try not to, but I catch myself being more lenient at times with my child who has the hearing loss."

~ "The discipline is the same. I won't let my deaf daughter go undisciplined for something that any other child would need discipline. I care about her future. And that involves making sure that she does not grow up spoiled or thinking that she can behave in a way that is socially unacceptable or do things that are wrong just because she has a hearing loss

~ "I think we may be easier on her, but I think that is more because she is a girl."

~ "We worked really hard not to treat our hard of hearing child differently. However, since she couldn't be yelled at across the room, there were probably times when she escaped some of the verbal "discipline" the others got."

~ "I would say that the answer to this question is yes. Our hearing children, because they have so much more vocabulary, can reason things out much better at a younger age than a deaf child can. They hear, 'No, you're going to get hurt if you do that,' or something similar to that, many times a day and after awhile they know they'd better not do that. With our deaf child, again, because he didn't know the words, we had to make sure that we got the point across in a way that he could understand. That included using sign, mime, conveying in whatever way we could that what he was doing was wrong and why. It takes extreme patience and understanding in taking the time to explain."

~ "Because I sign with my child, it requires stopping everything in order to have my hands free to sign. It takes a lot of patience, but I think it has helped me do a better job with both of my children."

~ "I'd like to think the answer is no, but I know there have been times when I have not disciplined my daughter for things I might have disciplined my hearing son for. Usually the reason has been because I felt that she truly did not understand what she did wrong, and in that situation I felt it was more productive to teach her about why what she did was wrong rather than to just punish her."



- Can you offer any tips on discipline for new parents?

~ *"Be extra patient, but don't let them use their impairment as an excuse for bad behavior. Remember, it's possible that they didn't understand the rules, so make sure things are clear, but then follow through."*

~ *"Rather than just saying or signing 'NO!,' offer an explanation to your child. Deaf children want more than a command. Discipline is a great time to communicate, so don't miss the opportunity."*

~ *"Develop a means of effective communication with your hard of hearing child. Do not encourage him to use the hearing loss as a crutch or excuse."*

~ *"Sometimes we have found that we have to act it out in mime even to convey what we are trying to say to our child. Show your child what he is doing, what it is doing to the person he is hurting, and what the results are. When you are sure he understands you, warn him that there will be consequences if he does it again. He will get frustrated if you say, 'No, No' all the time or discipline him for something he did if he didn't understand your reasoning behind it. Picture it - all he sees is your mean face with your mouth moving. He might not even understand why you are mad at him."*

~ *"Too many parents get hung up on the words deaf or hard of hearing and forget that the child needs structure, discipline, and responsibility."*

~ *"Expectations should be the same for deaf and hard of hearing kids as they are for hearing kids. Lacking discipline because of feeling sorry for the child with the hearing loss will only hurt the child in the end, possibly causing behavior problems and problems with peers."*

~ *"Don't feel guilty for disciplining your child. You are doing the best for them by training them to be decent human beings and giving them the best opportunity to grow up and become what you would want them to be. Discipline is a fundamental part of your love for them."*

~ *"Working so hard to hear and understand all the time can be exhausting. Be tolerant when your hard of hearing child has had a long day at school, because they have had to work much harder than others just to get through the day."*

~ *"You need to understand your child's personality and work with that. Also, make sure you get down to their level when speaking to them."*

GETTING EXTENDED FAMILY MEMBERS INVOLVED

Many of the same issues and concerns arise when talking about raising a child who is deaf and raising one who has a milder degree of hearing loss. However, because some children have residual hearing and benefit from the use of amplification devices, their communication and educational needs are different from those who are deaf. Often these children are able to communicate through spoken language.

Hard of hearing children face their own set of challenges, as do their parents. To address these individual concerns of parents with deaf or hard of hearing children, the answer portion of the following section has been separated into two categories: 1) For parents of hard of hearing children, and 2) For parents of deaf children.

- What techniques do you use to get extended family members (grandparents, aunts and uncles, cousins, etc.) to interact with and communicate with your deaf or hard of hearing child? What works and what doesn't work?

(for parents of hard of hearing children)

~ "Our extended family, friends and neighbors have learned to be sure Matt is looking at them...not turning their back when speaking, and sometimes restating for understanding, especially when Matt was younger. When we are swimming and the 'gang' is doing some kind of water play, friends sometimes need to be reminded that no matter how loud they yell, Matt doesn't know what they are saying unless he can look at them and read their lips."

~ "I discussed with them his hearing loss and how to better communicate with him. For example, do not yell across a noisy room and expect my child to respond. You must go to him and communicate face to face. Hard of hearing and deaf children learn visually. They need to see your face. Do not get upset if he does not respond, because you need to check in with him and see if he understands, and allow him to communicate back to you. This also builds his vocabulary. I think education is the key, but don't overwhelm them with the small details. Tell them what your child needs from them."

~ "We encouraged them to talk to our child, not through us. We tried to insist that she answers questions and we worked hard not to answer them for her. We included her in all conversations."

~ "We shared a lot with our extended family. We openly talked about difficulties and frustrations he experienced with communication. When people did not look at him when they spoke, we reminded them that he needed them to do that. WE tried to model effective communication techniques with our family members."



(for parents of deaf children):

~ *"I decided early on that I would not force anyone in my family to learn to sign, but encouraged them as much as possible. It has been interesting to see who has taken an interest over the years. My parents were wonderful. They hired a sign tutor to come to their home every week for several months to teach them, along with some of our other relatives and neighbors. Interestingly, those who have had the most contact with my child over the years, and have had the most opportunities to learn to communicate with her have not done so. In the end, they are the ones who are missing out. It is hard, but you have to accept that not everyone is going to take the time, and instead of wasting time being angry about it, it is much more productive to encourage and teach those who show the most interest, particularly the children in the family, since they are like sponges and are often very eager to learn new ways to communicate."*

~ *"Actually I have found this to be very difficult, frustrating, and at times hurtful. I explained the situation to all my friends and family. I felt that it was unfair to put pressure on them to learn sign, but certainly told them how important it was to me and to my daughter. I made time to teach sign language on a regular basis and shared what I was learning as I was learning it. Many of my family and friends were great and were dedicated to learning and have done well, and I am so grateful for them."*

~ *"My parents took sign classes from a friend of theirs in another state, and have been very excited to share with my child what they have learned. One thing that was hard for my sister was that she wanted my deaf child to stay the summer with her and I said I did not think it would be fair to my child to go some place where they wouldn't be able to communicate with her. That gave some of my family members incentive to want to be a part of my child's life."*

~ *"Going to family sign class was a good experience for my family. It made everyone feel more understanding and less threatened being around our daughter."*

~ *"We gave them sign books and videotapes. We also found it helped to let them take care of our child for short periods of time by themselves."*

~ *"With us this is a simple matter. We tell relatives, visitors, friends, everyone, that he cannot understand their words, only signing, and then we either translate for them or teach them how to sign what they are trying to say. It takes extra time, but it results in our son knowing that they care enough to learn to communicate with him. That says a lot."*

~ *"Hannah just signs with them as if they know how to sign. I encourage them to go to sign classes and I interpret for them. Sometimes I don't interpret so family understands that they need to get more involved."*

SIBLINGS OF A CHILD WITH A HEARING LOSS

- How do you encourage siblings to sign/communicate with their deaf or hard of hearing brother or sister?

(for parents of hard of hearing children):

~ *"With our son being the oldest, it has never been an issue in our family. His VERY bossy younger sister has needed a reminder on occasion that she is not the speech and language expert, and that corrections need to be made by the resident Mom or Dad!"*

~ *"I have never told them anything different than what I tell adults. I let my child explain to his brother why he wears hearing aids and how he should talk to him."*

~ *"We encouraged them from the very beginning. We modeled communication skills we learned at parent/infant classes. And we emphasized that they talk to her, even when it was easier and faster to communicate through a parent."*

~ *"Our hearing child picked up on many of the communication techniques as he grew up with his older brother, who is hard of hearing. When we saw him communicate in an ineffective way, we tried to correct him and asked him to repeat what he wanted to communicate using effective techniques."*



(for parents of deaf children):

~ *"When my daughter's hearing loss was diagnosed we explained the situation to her older sisters and talked about how we would need to communicate with her. We taught them signs and helped them along with new vocabulary as needed. It was a fun thing for them and they learned quickly."*

~ *"Our child needs sign language for communication, so when our hearing son was born we began signing and talking to him simultaneously. I think because it was something he was exposed to from birth, it became as natural for him to sign as it did to speak. He signed his first words at the age of 9 months (no, more, please), in fact, he signed before he spoke. Today, as a young adult, he is a fluent signer."*

~ *"Our son has multiple disabilities. We do the alphabet and colors with our hearing daughter, and we mainly encourage her to touch and play with her brother, and try not to overemphasize how fragile he is so that she is comfortable with him."*

~ *"When my hearing son was about 8 years old he came to me and said he was tired of signing. I explained to him that sometimes I got tired of it too, and that I knew that it could be difficult, but that in our family it just wasn't an option not to sign. I told him that he could learn to sign, but that his sister could not learn to hear. He seemed surprised to hear me say that I also got tired of signing sometimes, and once I had sympathized with him a little bit, it was never an issue that came up again."*

~ "We held sign classes for neighborhood children in the summer, and my son helped teach the classes. He distributed fliers, handed out lessons, and helped serve as a sign model. In this situation, he was the expert, and it made him feel very proud and important to be able to sign. After the first summer, he took it upon himself to teach the other children in the neighborhood to sign, and I have some very precious videotapes of him sitting on his chair in the driveway surrounded by a number of enthusiastic students."



~ "I tell them it is just what we do in our family, and they are so good at it."

~ "We held family sign classes and asked the siblings to teach some of the signs. This made them feel included and important. They also attended sign classes for siblings."

~ "We got involved as a family by taking sign classes together and by attending special meetings with parents and their children so that everyone got used to the fact that if they wanted to communicate with their brother, they had to learn his language."

Do you think you place more responsibility on your hearing children than your deaf or hard of hearing child? If so, why? If not, why not?

~ "I'm sure that I have at times. It is much easier to get the attention of the hearing child. It takes more time and energy to go to the child with the hearing loss and explain what you need done, and when I'm in a hurry or tired, I find I will automatically call the hearing child to do the task. I'm sure if you ask my hearing child, he will say that he has more responsibility than his sister does. I'm more aware of doing this now, and I try to be careful not to do it."

~ "Sometimes we found ourselves asking less of our hard of hearing child in regards to tasks around the house when he needed to spend more time on homework."

~ "Both of my children had equal responsibilities when it came to things like cleaning their room and helping clean the kitchen. It sometimes took a little longer for my deaf child to accomplish the same task because I realized that I was taking for granted that she understood what was expected of her when giving her something new to do. I realized that I would often talk my hearing child through the same job while I was doing something else in a different room. Once I realized what I was doing, I began taking more time initially to explain the task better and model what needed to be done before expecting her to just wing it."

~ "Yes, unfortunately this has happened. Our hard of hearing child often became frustrated when helping with jobs at home, because it was difficult always to face him to give directions. As a result, it was easier to ask our hearing child to help with some chores."

~ "Maybe when they were very young, but our hard of hearing child is also the youngest, so that may have just been the natural thing to do. As she got older, we tried to give her more responsibility and to take more responsibility for her own communication with others."

~ "Inadvertently there is more responsibility on the hearing children for things like 'call me if...' when they were playing. When friends came, the hearing child automatically was expected to tell them what our deaf son was saying. It is enough responsibility just being the hearing sibling. Sometimes he feels he is unnoticed when people ask about our deaf child or he feels burdened because he must watch out for his brother's safety, etc. As far as placing more responsibility for doing chores or schoolwork on the hearing child, no! The deaf or hard of hearing child needs to be expected to do his share in the family, school, and community."



~ "Not really. I try to look at them for what they are and who they are. Their age is also very important and my husband and I try to give both of them responsibilities according to their age."

~ "Yes, because I think sometimes that my hearing child will understand me better and sometimes I get lazy with my signing and it is just easier to say it and have it done faster."

~ "One thing I decided early on was that I would be very careful not to put my hearing child in the position of having to be the interpreter, unless absolutely necessary. She does this enough in every day situations without being expected to do it for other things. It is tempting to let her interpret when we know she can do it, but it can lead to resentment."

~ "I feel that responsibility needs to be the same, whether a child is hard of hearing, deaf, or normal hearing. We all have to survive in the same world. What is most important is communication with your child so that he or she understands what the expectation is."

- What do you think your hearing children have learned from having a deaf or hard of hearing sibling?

~ "I know for a fact that my hearing child demonstrates much more tolerance and acceptance of people with a disability, as well as people who are different in any way, than most of his peers. He knows first hand that his sister is just like anyone else, but is perceived as different by people who don't understand deafness. I don't see him give in to peer pressure to tease those who are different from himself, and although this may just be part of his personality, I think it also has to do with the fact that he has a sibling who has a hearing loss."

~ "I think they have learned tolerance to some extent. They saw the struggles and how hard she had worked to succeed to become the teen she is today, so I think they feel a special pride in her accomplishments. But they don't cut her any slack!"

~ "I think most of all they have learned acceptance. The hearing loss is just a small part of who a person is. Aside from the disability, a person with a hearing loss is still a full and complete person."

~ "This is a very difficult question. I think she has learned that people can be different and function differently and yet be normal. She doesn't understand why other people don't understand that. She also had to learn something very hard, and that was the fear of losing her brother. This was because of the meningitis, not the hearing loss. Now she is very afraid whenever he gets sick and asks a lot of questions."

~ "Just because people may look or do things differently than you do, or that is out of the norm, doesn't mean that you can't be friends with them. I think they have learned a lot about acceptance and diversity and will continue to learn it as they grow older."

~ "Our hearing children have learned many things from having deaf and hard of hearing siblings. They have learned the importance of sounds and communication that they would otherwise take for granted. They have learned to be observant of the obstacles encountered, and have learned to explain things to other people. They have learned to clarify and explain more fully to the deaf and hard of hearing children. They have learned that their deaf and hard of hearing siblings are able to do anything they work to achieve."

~ "They have learned about coping, and have learned that diversity is not so different."

~ "They have learned to appreciate disabilities, especially deafness. They have also learned that they couldn't always have as much attention as they wanted, and learned to be resilient and responsible, and hopefully learned how much easier things are when you can hear normally."

~ "Though we did not see it in the beginning, when we look back we can now see that having a child with a hearing loss has been a real blessing to our family. It teaches compassion and draws out some of the best qualities in a person. Love, patience, and empathy for others, are only a few of the traits we see developing in our children. It has become one of the binding forces holding our family together, all wrapped up in our precious little one!"



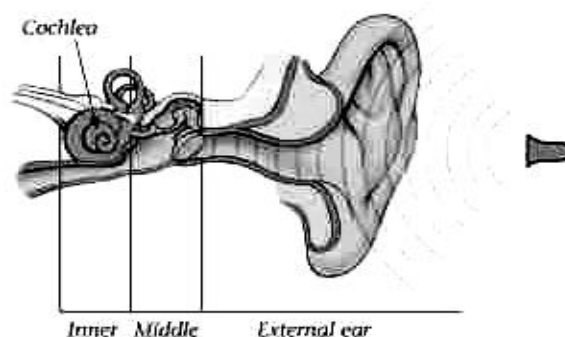
FOR MORE INFORMATION ON PARENT SUPPORT SEE THE
RESOURCES SECTION AT THE END OF THIS BOOK.

HEARING AND HEARING LOSS

HOW WE HEAR:

The ear is commonly described as having 3 sections: The OUTER (EXTERNAL), MIDDLE, and INNER EAR.

The OUTER EAR funnels the sound waves of sound vibrations down through the ear canal causing the eardrum (tympanic membrane) to vibrate. This vibration causes the three MIDDLE EAR bones (ossicles) to vibrate, which amplifies the incoming sound. This creates movement of the fluid in the INNER EAR (cochlea), which sends nerve impulses to the brain. Once the brain receives the impulse, we have a sensation of sound.



TYPES OF HEARING LOSS:

Hearing loss can occur in either the outer, middle, or inner ear.

Conductive Hearing Loss

If there is a problem in the OUTER or MIDDLE EAR, a *conductive* hearing loss exists. This means that the outer or middle ear problem impedes the sound, that sound cannot be conducted into the inner ear. Common causes of conductive hearing loss are wax, fluid, damaged eardrum or ossicles. A conductive hearing loss can also be caused by an anatomic abnormality, either the absence of an opening to the ear canal, an absent or incomplete outer ear, or absent or incomplete middle ear system. This type of hearing loss is usually medically or surgically treated.

Sensorineural Hearing Loss

If there is a problem in the INNER EAR, the hearing loss is *sensorineural*. Common causes of sensorineural hearing loss are pre-natal infections, lack of oxygen, genetic factors, and abnormalities or diseases affecting the cochlea. Sensorineural hearing loss usually cannot be cured medically or surgically. Hearing aids or other amplification systems, such as assistive listening devices and cochlear implants, can help children hear better and develop speech and language.

Mixed Hearing Loss

If the hearing loss involves both a conductive problem and a sensorineural problem, the hearing loss is known as a *mixed* hearing loss. The conductive component may be medically or surgically treatable.

DEGREE OF HEARING LOSS

Hearing loss is categorized as ***Mild, Moderate, Severe or Profound***. Hearing loss can be entirely within one category, or pass through several across frequencies; For example, a child can be described as having a “mild-moderate hearing loss”, or a “moderate-to-profound hearing loss”. See the section entitled **Effects of Hearing Loss on Speech, Language, and Education** for more details about the impact of the various degrees of hearing loss.

EFFECTS OF HEARING LOSS ON SPEECH, LANGUAGE, & EDUCATION

MILD HEARING LOSS (25-40 decibels/dB)

- Receptive:**
- May have difficulty hearing soft or distant speech and will benefit from hearing aids and assistive listening devices.
 - Child is likely to miss short unstressed words.
 - Voiceless consonants (e, g, f, k, p, s, t) are not always heard as clearly as vowels.
 - Background noise blocks out speech sounds. In quiet, will be able to carry on a conversation.
- Expressive:**
- May not use voiceless consonants or unstressed syllables.
 - Vocabulary and language may be limited with word endings or whole words left out.
- Education:**
- Needs favorable seating and lighting in school.
 - May need to speechread to increase understanding of what is said.
 - May need speech therapy to correct mispronounced sounds.

MODERATE HEARING LOSS (40-60 dB)

- Receptive:**
- Will miss almost all speech at a conversational level unless the speaker is very close.
 - Will benefit from hearing aids and assistive listening devices.
 - At close range (3-5 feet), speech must be loud to be understood.
 - Vowels are heard more easily than consonants.
 - Will miss word endings, prepositions and unstressed syllables or words.
- Expressive:**
- Will omit and distort consonants and be difficult to understand.
 - Special training is needed for speech development along with amplification. May have difficulty with multiple meanings and idioms.
 - Vocabulary will be limited.
 - Omissions include articles (a, the), conjunctions (but, or) and prepositions (on, in).
- Education:**
- May miss as much as 50% of class discussion if voices are faint or not within the line of vision.
 - May demonstrate inattention and need preferential seating and special training in how to listen and speechread.
 - Will benefit from the use of FM auditory training unit in the classroom. May need speech therapy, tutoring in reading, and vocabulary development.

EFFECTS OF HEARING LOSS ON SPEECH, LANGUAGE, & EDUCATION (CONTINUED)

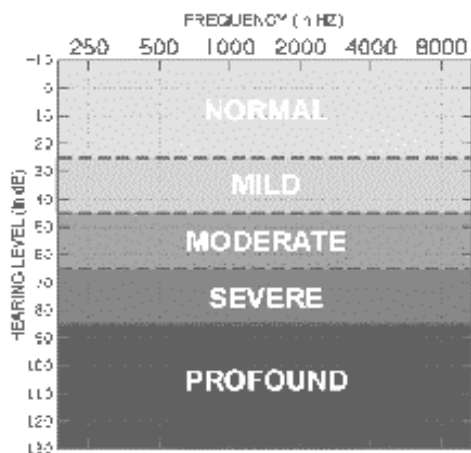
SEVERE LOSS (60-90 dB)

- Receptive:**
- May hear a loud voice, but not understand speech or discriminate between consonants.
 - Will benefit from hearing aids, assistive listening devices and possibly a cochlear implant.
 - Hears environmental sounds such as a door slamming, but cannot hear a conversation without amplification.
 - Understands very little without visual and contextual clues.
- Expressive:**
- Speech and language will not develop normally without amplification and special training.
- Education:**
- Will benefit from the use of an FM auditory trainer in class.
 - Will likely need special help in language, grammar, vocabulary, reading and writing.
 - Must learn to attend to auditory and visual aspects of situations at all times.
 - Educational program will need supervision and comprehensive support services.

PROFOUND LOSS (90 + dB)

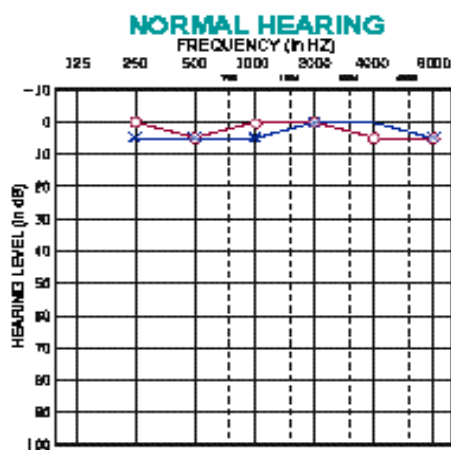
- Receptive:**
- Hears no speech sounds without amplification.
 - Will benefit from hearing aids, assistive listening devices and possibly a cochlear implant.
 - May hear loud sounds, but is aware of vibrations more than tones.
 - Relies on vision rather than hearing as primary avenue for communication.
- Expressive:**
- Articulation, pitch, and rhythm will probably be poor.
 - Does not develop speech naturally without amplification and special training.
 - Severe language delays possible.
- Education:**
- Educational program needs specialized supervision and comprehensive support services.
 - FM auditory trainer may be helpful in class.
 - Part or full time in regular classes with an interpreter and/or tutor is possible for a limited number of children.

WHAT IS AN AUDIOGRAM?



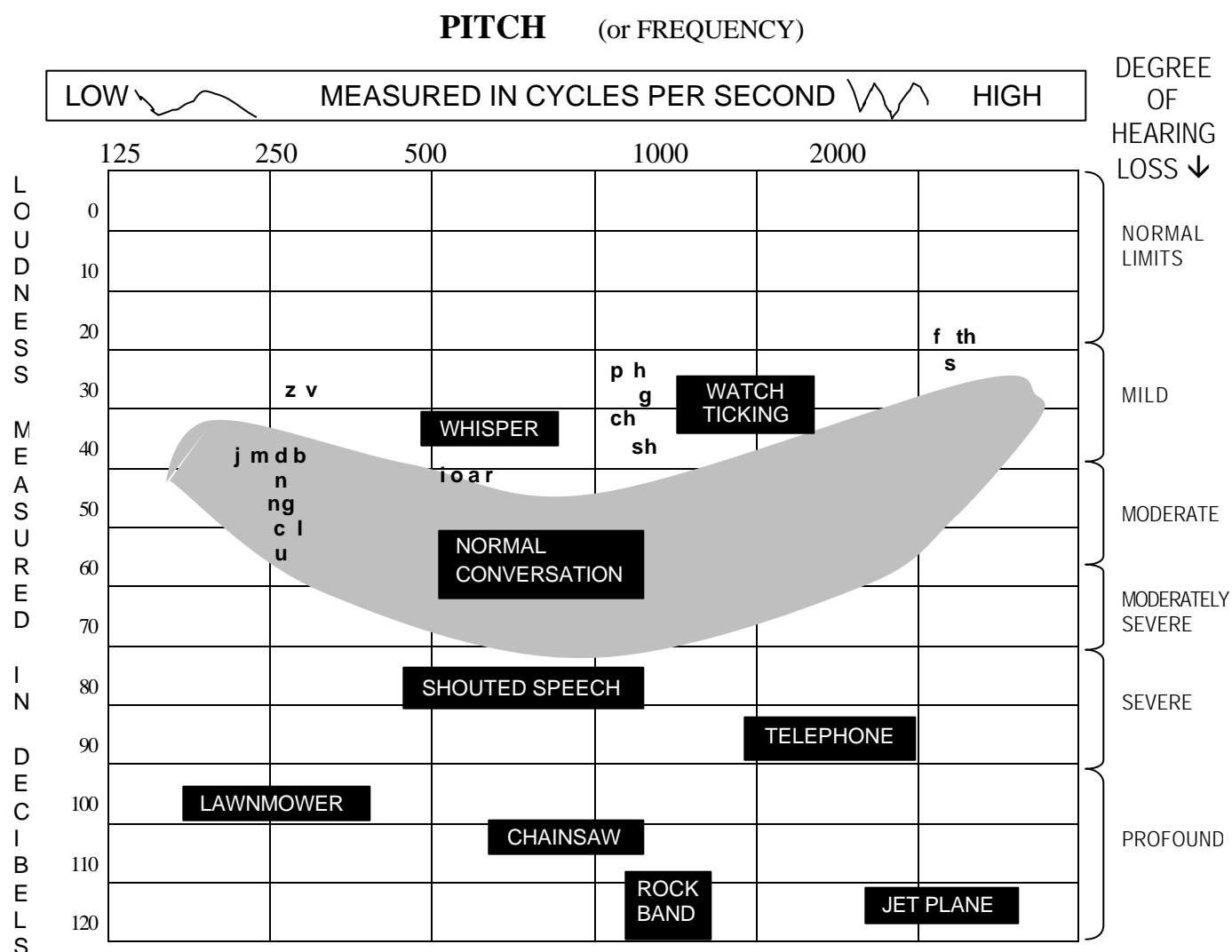
The pediatric audiologist will measure your baby's hearing and plot a graph called an audiogram. An audiogram is a graph used to show the softest sounds that a person can hear at different pitches.

Humans can hear sounds in the pitch or frequency range from 20 to 20,000 Hz. The pitch range that is most important for hearing and understanding human speech is from 250-6000 Hz.



This audiogram shows normal hearing.

The audiogram on the following page shows the pitch and loudness of many sounds, including conversational speech sounds and environmental sounds.

Audiogram with Various Environment and Speech Sounds

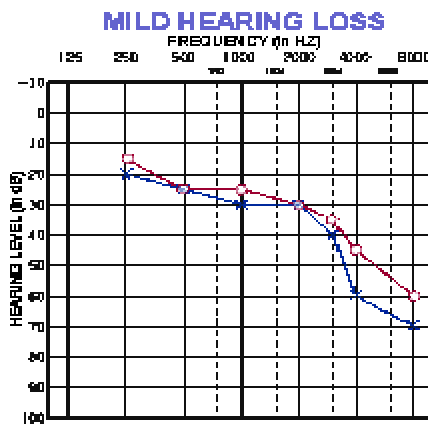
The shaded 'banana shaped' area on the graph shows the range of sounds included in typical speech. Different sounds in our language vary in their pitch and loudness. For example, the "s" sound you use in the word "cats" is high in pitch and fairly soft. In contrast, the "o:" sound in "bow" is low in pitch and fairly loud. The frequency and loudness of individual speech sounds are also shown on the audiogram.

(Shaded region on audiogram shows the level and frequency of normal speech)

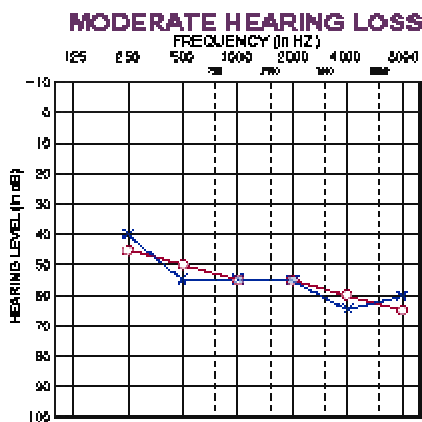
LOUDNESS LEVELS OF COMMON SOUNDS (in decibels)

10 dB	Breathing	80 dB	Rush Hour Traffic	120 dB	Jet Airport
30 dB	Whisper	90 dB	Food Blender	140 dB	Shotgun Blast
70 dB	Typewriter	100 dB	Train		

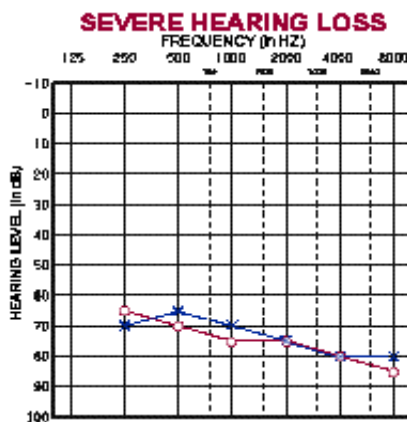
AUDIOGRAMS, CONTINUED



This audiogram shows a mild high-frequency hearing loss. A child with this degree of hearing loss will have trouble hearing and understanding soft speech, speech from a distance or speech in a background of noise and will benefit from hearing aids and assistive listening devices.



This audiogram shows a moderate high-frequency hearing loss. A child with this degree of hearing loss will have difficulty hearing conversational speech even at close distances and will receive some benefit from hearing aids and assistive listening devices.



This audiogram shows a severe to profound hearing loss. A child with this hearing loss may only hear very loud speech or loud environmental sounds. They will receive some benefit from hearing aids, assistive listening devices or possibly a cochlear implant.

AUDIOLOGICAL TESTING BY THE PEDIATRIC AUDIOLOGIST:

Birth to 6 Months:

ABR: Currently, a diagnostic auditory brainstem response (ABR) evaluation is the only method available to accurately diagnose hearing loss in newborns and infants. This test is painless, non-invasive, and without risks to your child's hearing. While this test is similar to ABR screenings often performed in newborn nurseries, the diagnostic ABR gives more detailed information about the degree of hearing loss across frequencies in both ears. This is also known as a frequency specific ABR. An Audiologist interprets the diagnostic ABR. Under 4 months of age, this test can be performed while a baby is sleeping naturally. If a baby is older or very active, a mild sedative may be prescribed to help the baby sleep. For this test, small sensors (electrodes) are placed behind each ear and on the baby's head. Sounds are presented to the ears with earphones; the electrodes pick up the response of the hearing nerve and send it to a computer to be analyzed.



OAE: Otoacoustic Emissions testing assesses the function of the cochlea, specifically the hair cells of the inner ear. The test is also painless, non-invasive, and risk-free. It is the most common screening test used in nurseries to identify children with possible hearing loss. To perform this test a small earpiece is placed in the baby's ear canal. A soft sound is presented, and if hearing is normal an "echo" occurs which is picked up by the microphone. OAE's can determine if the nerve cells of the inner ear function normally. However, the response is easily affected by middle ear obstructions, such as fluid or wax. Therefore, a non-response is inconclusive and must be followed up by a diagnostic ABR.

TYMPANOMETRY: This test measures the flexibility and condition of the middle ear system. The results are plotted on a graph known as a tympanogram. If your child has a middle ear infection or fluid, the test will indicate that. A tympanometer is used to assess middle ear function; a small rubber earpiece is placed in the ear canal. The test is very quick and painless. Air pressure is introduced in the ear canal to gently vibrate the eardrum and move the middle ear bones. Tympanometry is not a hearing test; it can tell us how well sound reaches the inner ear, but it does not tell us if the inner ear can hear that sound.

AUDIOLOGICAL TESTING, continued

6 Months to 2 Years:



VISUAL REINFORCEMENT AUDIOMETRY (VRA):

Infants and toddlers older than 6 months can be tested using a behavioral technique known as Visual Reinforcement Audiometry. With this test, a sound is presented either through earphones or speakers.

The child is trained to search for the source of the sound and then rewarded by an animated toy. Using this technique, it is possible to obtain detailed information about the child's hearing across frequencies in both ears. Test results are plotted on an audiogram.

2 Years to 5 Years:

CONDITIONED PLAY AUDIOMETRY (CPA): Young children can be tested using Conditioned Play Audiometry. This is a game-like activity where the child is trained to wait and listen for a sound and then perform a specific task when she hears it; For example, dropping block in a bucket, stacking rings or pegs. As with VRA, it is possible to obtain detailed information about the hearing loss across frequencies for both ears. In addition, specific information regarding speech discrimination can be also be obtained.



QUESTIONS ABOUT HEARING AIDS FOR CHILDREN

WHEN SHOULD MY CHILD GET A HEARING AID?

Newborns have their hearing tested at birth and can be fitted with hearing aids within a few weeks. Research shows that fitting a hearing aid as soon as possible helps to minimize the effect of the hearing loss on language development. Ideally your infant will be fit before 3 months of age and no later than six months of age. In consultation with the audiologist, you should come to a careful decision regarding amplification after consideration of your infant's individual needs, including the characteristics of the hearing loss and available technology, as well as financial resources. As more specific information about the hearing loss is obtained, the hearing aids will need to be adjusted. Your audiologist will perform tests with the hearing aids on your child to further confirm the fitting benefit. Hearing aids do not restore normal hearing and your audiologist will explain the realistic expectations, benefits, and limitations for your

MYTH: *nothing can be done about a hearing loss until the child is older.*

FACT: *Infants can be fitted with hearing aids as early as one month old.*

"The earlier a baby starts to listen and the earlier there is language in the baby's environment, the sooner language, speech, and listening can develop."

Boys Town Research Hospital

child.

WHAT ARE THE DIFFERENT TYPES OF HEARING AIDS?

A hearing aid is a device for the ear, which makes sounds louder in the range of a particular hearing loss. The goal is to provide your infant with the ability to hear speech and environmental sounds at a comfortable level. If your infant's hearing aid is fitted with a telecoil, when the time is appropriate, the aid can be directly coupled to a hearing compatible telephone or to an assistive listening device. Hearing aids vary by type of fitting and the type of technology used.

BEHIND-THE-EAR HEARING AIDS: (BTE). A BTE is positioned behind the ear and coupled to the ear with a custom fitted earmold. Typically, young children will be fit with behind-the-ear hearing aids because of the following features:

1. BTE earmolds are made from soft materials, which are more comfortable and less easily broken, for physically active children.
2. Earmolds can be replaced as the child's ears grow. It is not necessary to recase or replace the hearing aid itself and the aids as well as the earmolds are available in colors and accessories designed specifically for children.
3. BTE hearing aids are often more reliable and less easily damaged.
4. BTE hearing aids with telecoils are easily connected to an assistive listening device.

IN-THE-EAR- AND IN THE CANAL HEARING AIDS (ITE & ITC): ITE's fit completely into the outer ear and are not recommended for children until at least 9 years of age. Young children grow quickly, and this means that an ITE would need to be re-made almost every 3 months. Another reason this type of aid is not appropriate is that they may not provide enough power for severe and profound losses. In the canal and completely in the canal hearing aids are not practical for infants or young children.

PROGRAMMABLE HEARING AIDS: Most hearing aids use computer programmable settings and adjustments so that very specific, tailored fittings can be made for a child's individual hearing loss. Using a computer, the audiologist can adjust the response of the hearing aid at multiple frequencies and for multiple input levels. They are especially appropriate for young children where there may be limited information about the child's residual hearing. A programmable aid gives the audiologist the flexibility to adjust the aid as more information is obtained or if hearing levels fluctuate or become worse over time.

DIGITAL HEARING AIDS: Digital hearing aids have additional features that may benefit the speech and language development of children, such as automatic volume control, speech enhancement, noise reduction, and feedback cancellation. Digital hearing aids convert sound waves into digits (stream of numbers), which are manipulated not only to amplify sound to comfortable levels, but also suppress background noise. Basically a digital hearing aid is a miniature computer. It provides more clarity than an analog (non-digital) hearing aid, and when speech is perceived more clearly, a child will be at an advantage in developing spoken language.

COCHLEAR IMPLANTS:

The Food and Drug Administration regulates the use of cochlear implants. The recent lowering of the age at which a child can receive an implant provides parents with another choice for their child who has a severe to profound sensorineural hearing loss. A cochlear implant is a surgically implanted device that transmits electrical stimulation directly to the inner ear. It can provide partial hearing to profoundly hearing impaired individuals. There are two components to the implant, one internal and one external. The external microphone picks up speech and sounds, which are converted into electrical signals by a speech processor (a small box worn on the body). The electrical signals are transmitted through the skin to the internal receiver, which sends the signals to the electrodes implanted in the inner ear. These electrodes signal the auditory nerve that a sound has been received. The cochlear implant is different from a hearing aid, because it does not make sounds louder. It bypasses the non-functioning part of the inner ear to electronically stimulate the nerve and produce a sensation of sound and improved sound awareness.



A family must work closely with their child's audiologist, physician, speech pathologist and teachers to determine whether or not their child is a candidate for this procedure. Cochlear implants do not provide normal hearing.

The benefits vary from person to person and depend on: the age at the onset of hearing loss, the age at implant, the condition of the cochlea, and the motivation of the individual and family, as well as education, support and training. The Food and Drug Administration (FDA), the federal agency responsible for regulations in this area, has established basic eligibility guidelines.

To be eligible for an implant a child must:

1. Have a severe to profound sensorineural hearing loss in both ears;
2. Be at least 12 months of age (age criteria has been lowered in recent years and may change again);
3. Can receive little or no useful benefit from hearing aids. This can be shown by a lack of progress in the development of simple auditory skills when using hearing aids;
4. Have support from an educational program that emphasizes the development of auditory skills (even if sign language is also used);
5. Have no other medical issues that may complicate the surgery or rehabilitation;
6. Have a family that is committed to provide support needed for the child to receive intensive speech and language therapy.

Children with implants should have support from a program which can provide intensive speech and language therapy to maximize the use of the implant along with ongoing monitoring of the device to help children make sense of the many sounds in their environment that are detected through the implant. This should involve auditory training several times per week and does not eliminate the need for a specialized educational program.

Parents who evaluate the possibility of a cochlear implant for their child may decide for or against an implant for many reasons. The critical issue regarding their decision is whether or not they have sufficient information about all the factors that influence whether or not their child can benefit from an implant. There are many resources available to assist parents in making this decision. Please refer to the resource section.

WHAT OTHER ASSISTIVE DEVICES MIGHT BE OPTIONS FOR MY CHILD?

The 1997 amendments to IDEA strengthened the mandate that multidisciplinary teams must consider whether a child requires assistive technology devices or services and must consider the communication needs of all children. *An assistive technology device is any item, piece of equipment used to increase, maintain, or improve the functional capabilities of a person with a disability.* An assistive technology service is any service that directly assists a person with a disability to select or use an assistive technology device. Assistive Technology is redefining what is possible for infants and toddlers with disabilities or developmental delays. Rapid changes in technology provide creative and effective solutions to enhance a child's potential development. In many instances, technology is a necessary component of a meaningful and appropriate early intervention plan.

Mastering the developmental milestones of early childhood is critical to the growth, health and independence of all children. Missing the opportunity to reach these goals, because of the lack of appropriate assistive technology, is unfair to a child with a disability and their family. Research in the field of assistive technology (AT), shows that mastery of certain prerequisite skills or typical developmental milestones is not necessary in order for children to make use of assistive technology. For example, it is not necessary for a child to master dialing a telephone to make a call, before he can benefit from having a phone conversation. Talking to friends and relatives after someone else has made the call provides a great opportunity for the child to experience using the telephone to communicate with others. Many professionals feel that early use of simple AT devices helps children use complex devices later on.

Assistive technology devices can provide access to the environment for infants and toddlers with hearing loss. A hearing aid to provide amplification for a baby with hearing loss is the most commonly known AT device. The Idaho Assistive Technology Project has published an excellent resource manual titled *“Assistive Technology for Infants and Toddlers, A Handbook for Parents and Caregivers.”* They attribute changes in federal laws such as the IDEA amendments in 1997, and the advances in technology as being responsible for raising the expectations that technology will be a basic component of early intervention programs for children under the age of three.

Infants and toddlers who are eligible for early intervention services can have AT included in their Individualized Family Service Plan (IFSP)*. Some infants and toddlers have delays that are not significant enough, or are not yet significant enough to be eligible for IDEA early intervention services but may still benefit from using an AT device. In some cases, private insurance or medical assistance will pay for a device or a parent can choose to purchase a device directly for their child. In Idaho, United Cerebral Palsy of Idaho located in Boise has a special lending library where parents can borrow items such as: amplified telephones or visual alerting devices to signal the doorbell or phone is ringing. The Council for the Deaf and Hard of Hearing has 5 AT demonstration and loan centers where AT devices are available for loan and where application can be made for assistance in purchasing the device.

The type of AT to be included in the IFSP will vary from child to child. For children who are deaf or hard of hearing sensory enhancers can help them access their environments and communicate independently. Augmenting sound or using a visual alerting device can assist a child with hearing loss. AT devices in the home can help a child successfully explore and learn in his/her natural environment. Amplifiers, alerting systems, hearing aids, text telephones, TV listening systems, personal FM systems and other AT devices may all be appropriate for an infant in an early intervention program. For a child who is deaf or hard of hearing, the addition of visual alerting devices that makes them aware someone is ringing the doorbell or the phone, allows that child to be an integrated member of the family. They will not be left out due to lack of access to auditory stimuli such as ringing phones or doorbells. Different types of assistive technology devices are discussed in the following sections.

**IFSP's are explained more thoroughly in Section IV-EARLY INTERVENTION*

ASSISTIVE LISTENING DEVICES (ALD'S):

FM SYSTEMS: FM systems are a type of amplification device. They consist of a microphone, transmitter and receiver with a headset. The speaker wears a microphone and transmitter and sends the radio signal to the person wearing the receiver. The person wearing the receiver picks up the signal and hears the speaker as if they were only inches from the ear. The loudness and clarity of the voice is not affected by distance between the two individuals.

INDIVIDUAL LISTENING SYSTEMS: Personal listening systems are similar to the FM system but the microphone and headset are on one device. The user has the headset systems.

TELEVISION & RADIO: Amplification systems for radio or TV can help people who can't hear regular systems or must turn them up to the maximum sound to hear them. Some systems connect a headset directly to a radio or TV and some are wireless systems that use FM or infrared signals to transmit the sound to a headset worn by the person who is hard of hearing. This system allows other people in the room to hear the radio or TV at a volume that is comfortable for them. Some movie theaters, churches and auditoriums use similar systems.

TELEPHONE: Handset amplifiers for telephones allow a person to increase the volume of the sound coming over the handset. Some of the amplifiers are portable and can be snapped on any handset.



Teletypewriters (TTY), telecommunication devices for the deaf (TDD), and text telephones (TT) all refer to a device that has a typewriter keyboard and a visual display. The TTY user types the message to the TTY user at the other end of the phone line. Since a TTY can only communicate with another TTY the telecommunication relay system (TRS) relays conversations between a TTY user and a non-TTY user. To reach a relay system dial 711. All states now connect any call made to 711 to their state's telecommunications system.



SIGNALING DEVICES: Signaling devices are used to alert a hard of hearing person that a specified sound is occurring. These devices can monitor such sounds as door bells, a baby crying, an alarm clock, a smoke detector, the telephone ringing, etc., and announce the sound by using a visual or vibrating signal. Visual signaling devices might be switches attached to lamps that flash to alert the person to sound. Vibrating devices send a signal to a vibrating device as small as a watch or as large as one to fit under a mattress.

COMMUNICATION ACCESS REALTIME TRANSLATION - (CART): CART is a word-for word speech-to-text interpreting service for people who need communication access. A CART provider is trained to render instant speech-to-text translation on a computer monitor or other display. Unlike computerized notetaking or abbreviation systems, which summarize information for consumers, CART provides a complete translation of all spoken words and environmental sounds, empowering consumers to decide for themselves what information is important to them. CART is useful in a variety of settings, both for the individual and for larger groups. CART is also referred to as *real-time captioning*.

ASSISTIVE DEVICE DEMONSTRATION AND LOAN CENTERS**ASSISTIVE DEVICE PURCHASE PROGRAM**

The Idaho Council for the Deaf and Hard of Hearing has equipped five Assistive Device Demonstration and Loan Centers in Idaho. Any person, of any age, can visit to learn more about devices. Those centers also have applications available for people to apply for assistance to purchase an assistive device. The purchase program requires that the applicant pay part of the cost of the equipment. The amount they must pay depends on their income.

Many deaf or hard of hearing people, and/or relatives, are unaware of the devices currently available. The demo centers allow individuals to try out different devices and borrow equipment on a short-term basis for use at meetings, work or home prior to selecting what device to purchase. The center does not sell devices, but provides information on local resources and catalogs for devices and has application forms available for anyone needing assistance to purchase the assistive device.

Check the Resource Section or contact the Council for the Deaf and Hard of Hearing for more information.

(208-334-0879 or 800-433-1323 Voice, or 208-334-0803 TTY, or 800-433-1361 TTY)

HEARING AID LOANER BANK

The Idaho School for the Deaf and the Blind maintains a loaner bank of hearing aids to enable parents to try out different types of aids before deciding which type works best for their child.

Check the Resource Section for contact information for your region of the State, or contact The Idaho School for the Deaf and the Blind at (208) 934-4457

WHAT IS EARLY INTERVENTION AND WHY IS IT IMPORTANT?

Although you might have a lot of questions about your child's hearing loss and what it means for their life, rest assured that national and state leaders have already determined that your baby's success is important. Improving educational results for children with disabilities has been made an essential element of national and state policy to ensure that they have the same opportunities as children without disabilities. Early intervention is important to ensuring this equality of opportunity. The current federal law on providing early intervention services is The Individuals with Disabilities Education Act (IDEA), Part C, amended in 1997 by Public Law 105-17. In Idaho, state law also authorizes early intervention services for your child. *

The **Idaho Infant Toddler Program** in the Idaho Department of Health and Welfare (DHW) manages the provision of early intervention services in Idaho. All babies need to learn an incredible amount in the first few months and years of life; those with hearing loss require special assistance early in life so that they can develop to their potential. The Idaho Infant Toddler Program, a state-wide resource, provides a variety of therapeutic, educational and supportive services to help both the child and his or her family. The DHW Regional **Child Development Centers** provide services locally. Many of the early intervention services for children who are deaf or hard of hearing are provided in collaboration with Parent/School Advisors from the regional outreach programs of the Idaho School for the Deaf and the Blind (ISDB).

"The mission of early intervention is to support parents/families as they clarify their goals, acquire information, and develop skills to meet their family's needs"



* Additional information on IDEA and Idaho State law is included in the **RESOURCES SECTION**

Why is Early Intervention Important?

- Early care and education have a definite, long-lasting impact on how children develop, learn, and regulate their emotions. It plays an important role in healthy development.
- The human brain has a remarkable ability to change, but timing is crucial. A child develops faster during the critical years from birth to 3 than at any other time. Intensive, timely intervention can improve the prospects and the quality of life for many children.
- Early intervention is cost-effective. It can reduce or eliminate future need for costly special education and social services; minimizes the likelihood of hospitalization, incarceration, or institutionalization; and can maximize the potential for independence.

What is Early Intervention Service?

Early Intervention Services meet the individual developmental needs of each eligible child and the needs of that child's family. They are provided as quickly as possible after the need for help (a developmental delay, disability, or chronic medical condition) has been identified.

Services to families through the **Infant Toddler Program** help parents learn how to be most effective in supporting their child's development and connect them to other resources. All early intervention services must be agreed upon in advance by the child's parents, included on an Individualized Family Service Plan (IFSP), and be provided by qualified personnel.

Early intervention service providers, knowledgeable about newborns, help parents understand hearing loss and gain confidence as a parent of a deaf or hard of hearing child. These service providers will also guide parents in identifying their child's strengths and needs and help the child develop important language skills necessary to become part of the larger community.

Early intervention begins with a visit from an Early Intervention Specialist. She or he is part of a team of professionals, including an audiologist, communication therapist, primary care physician, an advocate of your choice, and most importantly, you

Services that must be provided by the **Idaho Infant Toddler Program** are listed in the Individuals with Disabilities Education Act (IDEA), Part C, and include those listed on the following page:

What services are available from the Idaho Infant Toddler Program?

If your child is eligible, one or more of these services may be provided:

- Developmental therapy;
- Speech/language therapy;
- Physical &/or Occupational therapy;
- Nutrition services;
- Social work services;
- Family education;
- Vision services;
- Assistive technology;
- Health services;
- Nursing Services;
- Hearing services;
- Diagnostic medical services;
- Respite care;
- Psychological services;
- Service coordination.
- Transportation services
- Other Professional services

See the 'Resources' section for more information.

ADDITIONAL SERVICES:

In addition to the services of your Service Coordinator, there are several services of other professionals you may need to call upon for you and your baby.

Your Service Coordinator can usually help you ask important questions as you look for the best audiologist or pediatrician. (The Resources section of this book also contains a listing of Audiological Centers serving Idaho.) In most Idaho towns, there is access to professionals who have experience with babies who are deaf or hard of hearing. They have worked with parents and children, and understand the questions and concerns you may have. They know how to provide appropriate treatment because they understand the effects of hearing loss on very young children.

You can also help doctors and audiologists update the skills they need. The Idaho Council for the Deaf and Hard of Hearing and the Idaho Sound Beginnings Program can provide educational materials for physicians and audiologists.

Services Coordination- Your Service Coordinator or Early Interventionist becomes a central point of contact between you and

the Infant Toddler Program and/or other professionals. This professional will work with you to identify and meet your baby's needs by coordinating both formal and informal supports and to assure that services are provided.

Assistive Technology - An assistive technology specialist can help you determine what type of assistive technology can benefit your baby.

Occupational or Physical Therapy -The cause of hearing loss may be the cause of motor or balance problems. Many young children benefit from early occupational or physical therapy.

Sign Language Classes or Teaching Materials-If you want to use sign language with your baby, you need to find a way to learn to sign as quickly as possible. Sign language lessons for parents of young children are sometimes available through Communication Education Programs or ISDB. The Meridian Public Library has an extensive video library available on inter-library loan to anyone in Idaho. Meeting deaf adults or participating in Deaf Clubs are other exciting ways to help the whole family become comfortable with signing.

**TWO MAIN GOALS OF EARLY INTERVENTION FOR BABIES WHO ARE DEAF
OR HARD OF HEARING:**

Give babies who are deaf or hard of hearing access to communication and the opportunity to develop language skills.

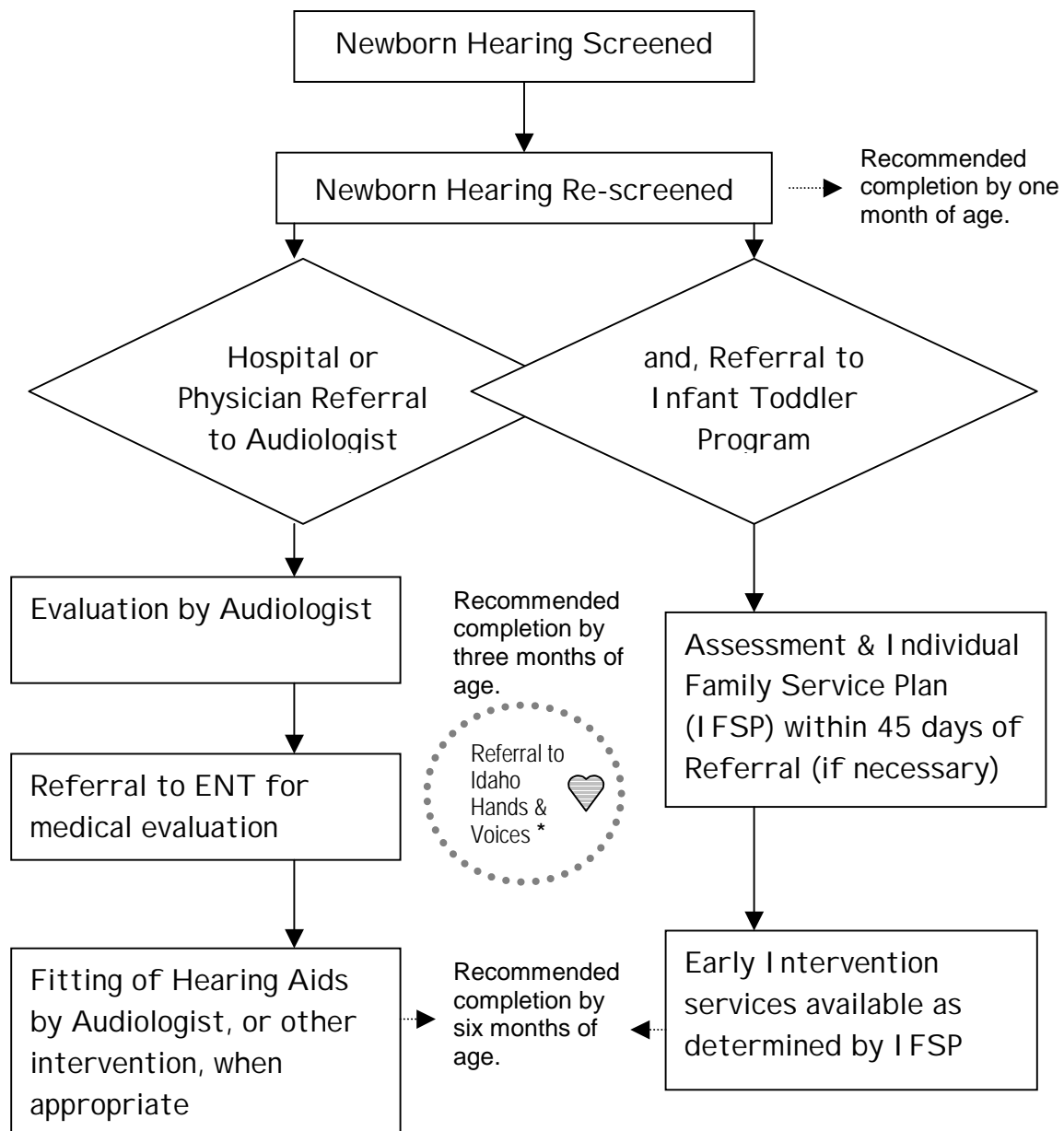
The human brain has a remarkable ability to change, but timing is crucial. A child develops faster during the critical years from birth to 3 than at any other time. Intensive, timely intervention can improve the prospects and the quality of life for many children. Children who are early identified and receive intervention prior to six months of age have significantly better receptive language, expressive language, personal-social skills, receptive vocabulary, expressive vocabulary and speech production.

Help babies who are deaf or hard of hearing become fully participating members of the family and later the community.

Everyone in the family is important to a baby's development, especially in developing language and social skills. For example, the baby needs to know what the family talks about at mealtime and what big brother and sister did at school. And, like all other young children, a baby should understand where the family is going when it gets into the car, when it's time to go to bed and when it's time to play, who Barney, the Teletubbies and Big Bird are and what they talk about.



**GUIDELINES FOR FAMILIES OF INFANTS WHO ARE
DIAGNOSED AS DEAF OR HARD OF HEARING**



- ▣ Continue Audiologic assessment and/or monitoring as needed,
- ▣ Early Intervention services are available to age three through the Idaho Infant Toddler Program, when determined by an IFSP,
- ▣ Deaf Education and/or other special education services available for age 3-21 when determined by an Individual Education Plan (IEP)



* See the Resources Section for contact information for IDAHO HANDS & VOICES local parent support.

HOW AND WHEN TO START EARLY INTERVENTION

The answer to the question "When?" is "Now!" The earlier that your baby starts communicating, the sooner language skills can develop! When you were notified that the hearing screening showed that further diagnostic testing was required, your baby became eligible to be referred to the Early Intervention program at the Department of Health and Welfare Child Development Center in your region. The goal of the Early Hearing Detection and Intervention (EHDI) program in Idaho is to have infants complete the diagnostic process by the age of three months and **to have them enrolled in Early Intervention by the age of six months.** *(Please see the RESOURCES section for a list of Infant Toddler Regional Child Development Centers with phone numbers)*

Assessment by the Early Intervention Specialist includes: observing your baby, reviewing reports from the audiologist and physician, asking you about signs of development, and helping you look for progress. Together you look for growing eye contact and use of gestures from your baby in response to your voice and/or signs. There are checklists of developmental milestones that you can update every week, every month, or every few months

Babies change so rapidly in their first months and years that you cannot wait a year to see if they are making progress. This is why ongoing assessments are done. The changes need to be described every day. At the beginning of Infant Toddler services, one of the most important results of assessment is information about how your baby likes to learn and communicate. It is important for you to pay attention to what your baby does and how your baby responds to you, so that you can understand how to encourage their communication. Based on ongoing assessments of how your baby is doing, you can continually refine your communication enhancing skills, or you can made changes in how you communicate with your baby.

Why not wait until my child is older?

Early Intervention is critical during the first three years of your child's life because:

- ▣ The foundation for communication, motor, social and self-care skills is developing;
- ▣ Thinking, talking, learning and moving skills develop rapidly; and
- ▣ Providing services now may reduce or eliminate the need for other costly services later. *

* Idaho Infant Toddler Program

YOUR EARLY INTERVENTION SPECIALIST:

In Idaho, services for children age 0 to 3 years are available through the Department of Health and Welfare's Infant Toddler Program and the Idaho School for the Deaf and the Blind. A professional will be assigned to come to your home and support your family in working with your baby. The professional may be an Early Intervention Specialist from the Infant Toddler program or a Parent/School Advisor from the Idaho School for the Deaf and the Blind Regional Outreach Program.

All children learn from their environment. Babies absorb language, thinking skills, and social skills as they experience the world with their caretakers and others. Most children acquire skills, especially language, effortlessly, because others are fluent in the language and use it all the time. Children who are deaf or hard of hearing can usually acquire language in the same way as hearing children, but they need a teacher, who is knowledgeable about hearing loss and its effect on communication development, to help them access the language environment.

Your Early Interventionist or Parent/School Advisor will have special training to give you and your baby access to language. They can help parents turn their home into a good listening environment. Developmental Specialists can recognize the cues your child gives you about their best way of communicating and different ways for parents and children to communicate.

The following examples of the work of an Early Interventionist describe some of the ways she or he will help you and your family at home:

- Work with you to identify priority needs for the child and family. He or she will also work with you to evaluate the child's strengths and current developmental skills.
- Work closely with your family to address priority goals you have set for yourselves and your baby. He or she will work with you to evaluate the progress you are making and to set new goals
- Support you in communicating with your baby and encourage your baby's development through natural daily routines.
- Assist you in identifying sources of support, if this would be of help to you.
- Recognize your expertise as your baby's parent and strive to develop a comfortable partnership with you.
- Help you and your family choose the best methods of communicating with your baby and support you in evaluating how your child is responding.
- Watch as you interact naturally with your baby, pointing out the many positive things you already do to support your baby's learning and suggesting additional techniques to encourage the baby's listening, babbling, watching and learning.

THE HOME VISIT:

The goal of the Early Interventionist or other professional is to work with you to help your baby grow and learn. Most therapy visits take place at home. Home is a "natural environment", a setting where babies are likely to spend most of their time. A natural environment can, however, be any place where a baby can play, communicate, and learn in the same way as other children. When a baby is deaf or hard of hearing, an environment may need to be modified/enriched to help the child communicate more easily. Babies who use hearing aids to understand language will need a quiet environment while they are learning to listen; they will also need someone to listen to the aids, check the batteries and put the earmolds in properly. Babies who use sign language will learn best when adults and children around them, especially family members, know how to sign. People at home and in the neighborhood need to learn to get a baby's attention, notice what the baby is looking at, and get down to the baby's eye level.

There are other natural environments, of course. Many small children go to playgroups or daycare. How good of a learning environment this setting is for your baby depends on how well the people there can communicate. Are there other adults or children who are deaf or hard of hearing? Can the staff learn to take care of hearing aids or to sign? Hearing children learn considerable language from their peers. If the deaf child uses sign language but no one else in the environment does, then the environment is no longer "natural." Sometimes, as babies become toddlers, a very natural environment can be a small group of other deaf or hard of hearing children who can play together, and receive the kind of help with language development that trained Early Interventionists and Teachers of the Deaf and Hard of Hearing can provide. A toddler playtime by itself is not enough stimulation for your child, but it can add some very special enrichment to the home visits and trips you take with your Early Intervention Specialist, your family, and your baby.



YOUR EARLY INTERVENTION TEAM:

Your early intervention team includes several key individuals called a Multi-Disciplinary Team (MDT) who will help build your baby's communication skills for the first important years.

No one person, especially one professional, should decide what is right for your baby. Professionals have good information and advice to offer, but a team of adults is more likely to make good decisions than a single person. You are an important member of the team. You can, and should, speak up for your baby.

Generally, members of your team will agree on the importance of your baby's needs, and a strong team can be a wonderful support for parents.

Team members and their roles may include:

You, as the Parent:

- You are the first and most important member of the team.
- No one knows your baby as well as you.
- You are there to observe your baby's development, from rolling over to sitting up, from standing to walking, from cooing and babbling to first spoken words and from gestures and pointing to first words in sign.
- You will be the person who puts on the hearing aids and talks, cues and/or signs to your baby throughout the day.
- You will be the person to tell other team members when the first words come.



Other professionals, however, know things that you are still learning about ways to help you and your baby communicate. They can answer your questions, and help you know what questions to ask.

Your advisor can give you information from many different sources, so that you can make the decisions for your child based on his or her individual needs. You will work with your team to become an advocate throughout your child's years of development. Teachers and team members will come and go, but you and your child will grow and develop together.

An Audiologist:

The audiologist is a very important member of the team. This individual keeps track of the amount of hearing your baby has, fits hearing aids, and answers your questions about hearing, hearing aids, cochlear implants, and other auditory equipment. They provide a "hearing home" for future questions and evaluations.

Your Early Intervention Specialist/or Service Coordinator:

When your child is three or older, this role may be filled by a classroom teacher of the deaf and hard of hearing or a speech-language pathologist. Early in your baby's life, you will need a person who specializes in helping families and babies get a good start. This person may have background in a variety of disciplines (e.g., teacher of the deaf, speech-language pathologist; audiologist, special education teacher, early childhood specialist) but will have special expertise in working with infants who are deaf or hard of hearing and their families. When your baby needs special services, someone with

authority to say that the Infant Toddler Program can and will provide those services needs to be at your Early Intervention (IFSP*) meetings. (*see TERMS AND DEFINITIONS)



A Communication Therapist:

Sometimes, your Early Intervention Specialist is a speech and language pathologist who has learned about aural habilitation. Most parent/infant teachers of the deaf and hard of hearing are also trained to help deaf and hard of hearing children begin to develop their voices and their hearing. For children who use cued or sign language, this team member will help you to begin

communicating with your baby as quickly and as easily as possible.

A Primary Care Physician:

Every baby needs a pediatrician or a family practice doctor. Some kinds of hearing loss occur with other medical issues. Doctors and geneticists can help you find or rule out other possible problems. You may be referred to an ear specialist, called an Otolaryngologist or ENT. The family practitioner or pediatrician provides a “medical home” for ongoing guidance and medical care in order for your child to grow up to be healthy and strong. Your primary care physician should approve and sign the Individualized Family Services Plan developed by your baby's team.



An Advocate

If you have another individual that you would like to be with you during meetings, you are free to invite your own advocate. This might be someone else in your family, an experienced parent of a child who is deaf or hard of hearing, someone who knows your baby well but is not usually on the team, or someone that you feel can help you to make appropriate decisions. Whether or not you bring an advocate is up to you.

Your Early Intervention Specialist/Service Coordinator will be able to help you get in touch with the other members of your team. It is a good idea to keep a list of team members with their phone numbers and e-mail addresses.



PARENT SUPPORT ORGANIZATIONS:

Your Early Intervention Service Coordinator can tell you how to get in touch with Idaho Hands & Voices and other local parent support groups. There is a Hands & Voices Parent Consultant in each of the seven regions where Early Intervention specialists are located.

Social gatherings and playgroups are also important support for families and babies. If you are learning sign language with other parents, sign class is a wonderful place to talk to mothers and fathers whose children are older, in preschool or in school, and who can give you advice and support. You can also meet other parents just starting out, who have made the same decision as your family, and are taking on the same challenges. If your baby is hard of hearing, it is just as important to meet other parents. Children who are hard of hearing have their own set of needs and their parents can always learn from each other.

If you want to find an adult role model for your child you can contact the Idaho School for the Deaf and the Blind Parent/School Advisor for some suggestions or contact organizations for people who are deaf or hard of hearing. The Idaho Association of the Deaf has a regional representative for each region of the state and is a good resource. Idaho has several chapters of a national self help organization for people with hearing loss called Self Help for Hard of Hearing People, Inc. (SHHH). Members of SHHH are often happy to help new parents understand hearing loss and may have adults who are willing to serve as role models for children with hearing loss.

It is important to realize that children who are deaf and hard of hearing grow up to be adults who work, drive, go to college, marry, have children, and in fact are not much different than the adults that hearing children become.

There are many support organizations in the United States. They may be regional, state, or national in scope. (See the listings in the RESOURCES Section of this manual)



YOUR BABY'S RIGHT TO EARLY INTERVENTION - THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

Background

The Education of All Handicapped Children Act (EHA) of 1975 otherwise known as PL94-142 mandated a free and appropriate education for all children with disabilities, ensured due process rights, mandated Individualized Education Programs (IEPs) and Least Restrictive Environment (LRE), and became the core of federal funding for special education. A multidisciplinary team must collaborate with the family to develop an **Individual Educational Program (IEP)** that includes all specific goals and objectives for a year. This part of the law applies to children from 3 to 21 years of age. Amendments in 1986 established Part H, which required early intervention services. For infants from birth through age two.



Individuals with Disabilities Education Act (IDEA)

In 1990 the EHA was renamed The Individuals with Disabilities Education Act (IDEA). It authorized the early intervention program that provides Federal assistance to help States maintain and implement a statewide system of early intervention services for young children with disabilities, aged birth through two, and their families (An amendment to IDEA in 1997 moved the early intervention requirement to 'Part C' of IDEA). The IDEA sets out eligibility conditions for State participation including—

- (1) a policy that ensures appropriate early intervention services for all eligible children, including, at State discretion, children who are at risk of experiencing substantial developmental delays; and
- (2) other requirements (e.g., provisions regarding individualized family service plans (IFSPs), natural environments, procedural safeguards, and financing of early intervention services).

The law focuses on professionals who give the family, as well as the infant, support and assistance. Evaluation of the infants and planning for intervention are to take place with a family, and the family must approve the final plans. A service coordinator helps families fulfill their needs by coordinating the work of team members and community resources. The infant's team works together with the family to develop an **Individual Family Service Plan (IFSP)**, which must include several important parts:

- Assessment of the infant's current achievements
- A list of family strengths
- Major goals, or outcomes expected from the program
- Specific services needed to achieve those outcomes
- Timelines for achieving goals
- A list of team members, and
- A plan for transition into preschool or some other program.

Your rights as
the parent of a
child eligible for
early intervention
services

Families have the right to:



Idaho Infant Toddler Program



For more information
on the Idaho Infant
Toddler Program,
see the
RESOURCES'
section at the end of
this book.

Give permission and consent: Before your child is evaluated or receives any services, you have the right to agree or disagree with recommended activities. You may refuse some activities without risking delivery of others. Participation in the Infant Toddler Program is voluntary.

Examine records: You have the right to look at any early intervention records concerning your child. You also have the right to request a copy of the records.

Privacy and confidentiality: Your child's records are confidential. No information about your child or family can be shared without your written permission.

Participate and receive support: You are a very important member of your child's early intervention team. Since you are the expert when it comes to your child, your participation in the evaluation, planning and implementation process is critical. You also have the right to bring a friend or advocate to any session.

Timely evaluation: Once your child is referred to the Idaho Infant Toddler Program and you give permission, your child will be evaluated to decide eligibility for the program. If your child is eligible, an Individualized Family Service Plan will be developed with you within 45 days. It outlines services for your child and family.

Be kept informed: Written notice must be given to you before services start or before any changes occur in the identification, evaluation, or services provided to your child. If your family's common way of communicating is other than spoken or written English, you have the right to be given the information in the way you can best understand.

Disagree and solve problems: You have the right to resolve concerns about the evaluation or services your child or family is receiving. For help, contact your child's service coordinator or the regional Early Intervention Specialist. Mediation services can be arranged. If the concern still is not resolved to your satisfaction, you may request a hearing. Send a written request with your concern to:

Idaho Infant Toddler Program, Attn: Program Manager
Department of Health and Welfare
450 W. State St., P.O. Box 83720
Boise, ID 83720-0036

EARLY INTERVENTION CHECKLIST:

1. Do I think that my baby might have a hearing loss? Call my doctor now!
2. Does my baby have a hearing loss? Call the Idaho Careline and ask how to obtain services. If you are having difficulty locating resources in the public school, talk with your audiologist or physician about other community programs. Ask to meet with another parent, if you feel that would be helpful at this time.
3. Are new people always being added to my baby's intervention team? Find out who they are from the service coordinator and write down their names, phone numbers, addresses, and e-mail addresses.
4. Is my family beginning to talk about goals for the baby and for us? Write them down and share them with the Early Intervention Specialist.
5. Am I beginning to notice so many little kinds of progress that I forget them by the end of the day? Start a diary and write just a few words about each one.
6. Have I found a pediatrician, an Ear, Nose and Throat doctor and an audiologist who really understand my baby and listen to me? Keep up the relationship.
7. Have I found support for my family and myself? Remember to take care of everyone's needs. Our whole family is important.
8. Have I received information about connection with other parents? Call the Idaho Careline (800-926-2588).

For further information on early intervention, family supports, or any of the other topics discussed in this section, please see the 'RESOURCES' section at the end of this book.

CHOOSING A COMMUNICATION METHOD

There are many ways to communicate with, or assist in communicating with persons with a hearing loss. The primary modes of communication and various options are addressed briefly in this section. To help make these decisions, first set your family's personal goals for your child's language access. You might consider:

- ✓ Is it important that your child speak English?
- ✓ What is your native/home language?
- ✓ How will your child and family interact with the deaf community?
- ✓ Do you desire your child to attend school with other deaf and hard of hearing children, or do you desire that your child attend community school or be home schooled.
- ✓ How will extended family, friends and society communicate with your child?
- ✓ Are there other spoken languages you desire your child to learn?
- ✓ Is your child in day care? What communication mode will best be able to be followed through in this setting?

After evaluating your answers to these questions, look for modes of communication that will best suit your goals and opportunities for communication.



It is important to make a decision, rather than no decision at all.

Deaf and hard of hearing children need early language and communication intervention in order to succeed in life. In making the choice for a method of communication, you must consider the amount of your child's hearing loss, the communication approaches and education programs available in your area, what suits your child, what you and your family can learn and follow through with, and many other factors. When you are faced with these decisions, ask as many questions as you need to understand each of these factors. Visit programs and talk with other parents and people with hearing loss. Compare the advantages and disadvantages of each possible approach for your child and your family. It is extremely important to make a choice, maintain interaction, and provide your child with clear and consistent language input.

No decision is irreversible. You may feel some consolation from knowing that you can review decisions about communication methods and educational programs each year. These decisions can be changed, as necessary, to provide your child with the best chances for success.



If you would like more information about communication methods, we recommend Choices in Deafness: A Parent's Guide to Communication Options, ed. Sue Schwartz, Ph.D. It is published by Woodbine House, Inc., 6510 Bells Mill Rd., Bethesda, MD 20817, (800) 843-7323. Your local bookstore or library may be able to order a copy for you.

AMERICAN SIGN LANGUAGE

WHAT IS MEANT BY AMERICAN SIGN LANGUAGE (ASL)?

ASL was developed by American Deaf people to communicate with each other and has existed as long as there have been Deaf Americans. Standardization began in 1817 when Laurent Clerc and Thomas H. Gaillaudet established the first school for the Deaf in the U.S. ASL is not universal. Deaf people in Mexico, France, and other countries use a different sign language from that used in the U.S.

WHAT ARE THE PRINCIPLES OF ASL?

Linguistic research demonstrates that ASL is comparable in complexity and expressiveness to spoken languages. It is not a form of English. It has its own distinct grammatical structure, which must be mastered in the same way as the grammar of any other language. ASL differs from spoken language in that it is visual rather than auditory and is composed of precise hand shapes and movements. ASL is capable of conveying subtle, complex, and abstract ideas.

WHO CAN USE THIS OPTION?

This method is used extensively within the Deaf Community, a group that views itself as having a separate culture and identity from mainstream society. Traditionally, the language has been passed from one generation to the next in the residential school environment. Approximately one-half million people in the U.S. and Canada use ASL. For those who wish to learn it as a second language, it takes many years of study and interaction with people who use it.

WHAT ARE THE BENEFITS OF THIS OPTION?

ASL is the language of Deaf people throughout the U.S. Proficiency in ASL automatically allows membership in the Deaf Community and in cultural events that occur in communities where Deaf people live. This membership can be vital to Deaf children because it promotes a healthy view of who they are as human beings and increases self-esteem and confidence in their abilities to interact in a wide array of situations.

WHAT ARE THE LIMITATIONS?

ASL has different parameters than spoken language and it cannot be used simultaneously with speech. Although there is extensive outreach to the hearing parents of Deaf children, it is unlikely that all parents will achieve fluency in ASL.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- What are the communication needs of the family?
- Are ASL classes available through local colleges or organizations for parents?
- What is the severity of the hearing loss and the potential for using residual hearing?
- What are the opportunities for peer interactions, communication, and cultural needs?
- For parents interested in this mode of communication, contact the National Association for the Deaf.

THE BILINGUAL-BICULTURAL /Bi-Bi Approach

WHAT IS MEANT BY BI-BI?

Bi-Bi is an approach to educating deaf children that incorporates the use of American Sign Language (ASL) as the primary language of instruction in the classroom. English is taught as a second language through reading and writing print. The Bi-Bi approach supports instruction in deaf culture, including the history, values and customs of the deaf community. In other words, Bi-Bi means learning two languages and two cultures.

WHAT ARE THE PRINCIPLES OF BI-BI?

The goals of a Bi-Bi education are to help deaf children establish a strong visual first language that will give them the tools they need for thinking and learning and to develop a healthy sense of self through connections with other deaf people. Bi-Bi advocates strong parent support through outreach programs, which encourage hearing parents to interact with deaf adults and other parents of deaf children to learn ASL and the culture of the deaf.

WHO CAN USE THIS OPTION?

Proponents of the Bi-Bi option feel that all children, no matter the degree of hearing loss, would benefit from a Bi-Bi option. These programs may be residential or day schools.

WHAT ARE THE BENEFITS OF THIS OPTION?

The Bi-Bi approach recognizes that ASL and English are two distinct languages. The programs advocate for ASL to be the first language of children who are Deaf. ASL is an efficient language for visual learning and easier to acquire as a first language than any form of English. Early access to comprehensible language fosters early cognitive development, which promotes increased literacy and greater academic achievement.

WHAT ARE THE LIMITATIONS?

Bi-Bi programs in North America are relatively new and research and evaluation are necessary to determine the effectiveness of the Bi-Bi model. There is also a need to develop and maintain curricula and training programs for teachers in these programs. There is also much controversy on the issue of how English will be taught. Methods that demand total immersion in English would seem incompatible with a Bi-Bi program. Other programs teach English through reading and writing.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- What are the communication needs of the family?
- What is the severity of the hearing loss and the potential for using residual hearing?
- How many of the educational staff are native ASL signers or fluent signers? How is English developed? How are children who developed language late or have limited language proficiency treated in this type of program? How is staff recruited and trained?

CUED SPEECH

WHAT IS MEANT BY “CUED SPEECH”

Cued speech is a sound-based hand supplement to speechreading. Eight handshapes, each representing groups of consonants, are placed in any of four positions around the face, which each indicate groups of vowel sounds. Combined with the natural lip movements of speech, the cues make spoken language visible.

WHAT ARE THE PRINCIPLES OF CUED SPEECH?

The purpose of this communication tool is to improve literacy rates among children, who are deaf or hard of hearing, by providing a phonetic foundation for language development that aids reading and writing. Cued speech has been adapted to approximately 60 other spoken languages. It is used in schools and programs for children who are hearing impaired, but its primary use has been within hearing families of young children who are hearing impaired and in regular education classrooms when those children enter school.

WHO CAN USE THIS OPTION?

Families of and professionals working with children with hearing losses, symptoms of autism, Down syndrome, deaf-blindness, cerebral palsy, and auditory processing deficits can use Cued Speech. Cued Speech is used by regular education teachers for phonics instruction, by speech therapists for articulation therapy, and by deafened adults to re-establish communication with their friends and family.

WHAT ARE THE BENEFITS OF THIS OPTION?

For families of children with disabilities, Cued Speech removes communication barriers. Normal interaction is restored quickly because the system is based on the family's native language. Once the system is mastered, any word in the language can be cued as well as environmental sounds, nonsense words found in children's literature, proper nouns, and the large number of English words for which there are no sign language equivalents. It provides a clear, visual foundation for reading and writing English. Children who have grown up using the system read and write on the same grade level as their hearing peers.

WHAT ARE THE LIMITATIONS?

While sounds that look alike are distinguishable by hand cues, lip movements are still an integral part of the system. Cuers must make lip movement and be within 20 feet of the cue-reader. The Cued Speech system is more than 30 years old, but the numbers of cuers and support groups varies throughout the U.S. The number of available “transliterators” (proficient cuers who cue what instructors say), while growing, is insufficient for the demand, primarily because Cued Speech students are usually mainstreamed in their neighborhood schools.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- Is this the most appropriate communication tool for our family to use?
- How long will it take us to learn and where can we learn it?
- Will we be committed to using it as much as possible as we interact?
- Is support available, and, if not, are we determined enough to do it on our own?
- What results can we expect from this communication tool?

AUDITORY – VERBAL

WHAT IS MEANT BY “AUDITORY-VERBAL” APPROACH?

The goal is for children who are deaf or hard of hearing to grow up in “typical” learning and living environments that enable them to become independent, participating, and contributing citizens in an inclusive mainstream society.

WHAT ARE THE PRINCIPLES OF AUDITORY-VERBAL PRACTICE?

- To increase the likelihood that young children who have hearing loss use their minimal amounts of residual hearing to learn to listen, process spoken language, and speak.
- Conduct an aggressive program of audiologic management.
- Seek the best available sources of medical treatment and amplification as soon as possible.
- Help the child understand the meaning of sounds and teach parents to make sound meaningful.
- The child’s parents are the most important models for spoken communication.
- Increase child’s awareness of own voice.
- Help children who have hearing loss participate educationally and socially with children with normal hearing.

WHO CAN USE THIS OPTION?

The auditory-verbal option is an early intervention strategy. It is not a set of principles for classroom teaching. The purpose is to teach auditory-verbal principles to the parents of very young children. Therefore, any family with a young child, regardless of the severity of the loss, can choose this approach. As with all early intervention programs, the earlier the child is identified, the better.

WHAT ARE THE BENEFITS OF THIS OPTION?

The majority of parents of children with hearing loss have normal hearing. Parents using this approach do not need to learn sign language or cued speech. In this program, parents are returned to their natural parenting role. The therapist works with parents so parents can model communication strategies with their child throughout the child’s daily life. Results of studies in the U.S. and Canada showed that the majority were integrated into “regular” learning and living environments. Graduates often had been mainstreamed in local schools and attended post-secondary institutions that were not specifically designed for the hearing impaired. Reading skills of auditory verbal children have been demonstrated to equal or exceed their hearing peers.

WHAT ARE THE LIMITATIONS OF THIS OPTION?

This approach depends highly on parental involvement. It is not a classroom approach, but a style of interaction between parent and child. If the parents are unable to commit to the intensity of involvement required, the child may not make as much progress.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- Where is the closest auditory-verbal center located?
- How much time will be involved at the center and at home?
- What is the relationship between the center/therapist and the school my child will attend?

AUDITORY – ORAL

WHAT IS MEANT BY “AUDITORY-ORAL” APPROACH?

The auditory-oral approach is based on the fundamental premise that acquiring competence in spoken language is a realistic goal for children who are deaf or hard of hearing. Further, this ability is best developed in an environment in which spoken communication is used exclusively. This environment includes both the home and classroom.

WHAT ELEMENTS ARE CRITICAL TO SUCCESS OF THE AUDITORY-ORAL APPROACH?

- Parent involvement and education are the basis for success. Acquiring effective speech and language requires that parents play an active role in their child's education.
- Appropriate and consistent use of amplification is important. Each child's needs are evaluated individually and monitored over time with modifications made as necessary. Hearing aids are the first choice; for children whose hearing loss limits the success of a hearing aid, cochlear implants are a viable option.
- Consistent quality speech training. Developing speech production skills requires skilled teachers who work with children wearing appropriate amplification.
- Range of placement option. Effective implementation of the auditory-oral approach requires that a continuum of placement options be available. Individual sessions for infants & caregivers, and self-contained or mainstreamed placements in school are necessary options.

WHO CAN USE THIS OPTION?

Given current amplification technology (i.e. powerful, flexible hearing aids, FM systems, cochlear implants) it is reasonable and realistic to expect most children with hearing loss to hear at conversational levels. This makes an auditory-oral education a possibility for the large majority of such children, with appropriate support.

WHAT ARE THE BENEFITS OF THIS OPTION?

The primary benefit is being able to communicate directly with a wide variety of individuals. This ability brings with it options in terms of education, vocation, and social life. There are also studies, which indicate that this approach results in more intelligible speech and higher reading levels.

WHAT ARE THE LIMITATIONS?

As with every approach to educating children, who are deaf or hard of hearing, not all children will be successful. Unanswered questions remain about auditory function, language processing, and learning styles.

WHAT ARE SOME QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

The primary question to ask is whether the philosophy and goals of auditory-oral education match the family's philosophy, goals and ability to participate in their child's education. If the answer is “yes”, consider the following: ***Does the school/program...?***

- Offer comprehensive parent education and support?
- Have an audiologist available?
- Have a consistent philosophy and practices which foster development of listening skills?
- Utilize a recognized speech curriculum for developmental progression of speech skills?
- Employ child-centered activities?

ENGLISH-BASED SIGN SYSTEMS

WHAT IS MEANT BY ENGLISH-BASED SIGN SYSTEMS?

Deaf people sometimes call ASL a natural language because it evolved through use. In contrast, educators developed English-based sign systems. These systems adopted much of the vocabulary of ASL, but added grammatical features of English such as articles (a, an, the), verb endings (-s, -ing, -ed, -en). English-based sign systems follow English syntax. One system that remains close to ASL is Signed English. A system no longer widely used, but extremely close to English is Seeing Essential English (SEE1). The most widely used system that is close to English is Signed Exact English (SEE2). Apart from specific vocabulary, all of the sign systems include the visual features of a signed language that add meaning and intonation to signing.

WHO CAN USE THIS OPTION?

Many parents and educators use english-based systems. Some Deaf adults have negative attitudes toward the use of such a system. They view it as a denial of Deaf Culture and of the child's deafness. Parents and educators, on the other hand, aim to expose the child to English in a clearly visible modality.

WHAT ARE THE BENEFITS OF THIS OPTION?

Children learn the language of their environment when they perceive it clearly. Use of an English-based sign system provides access to English during the language learning years. It can also be useful with older students who have not yet mastered English.

WHAT ARE THE LIMITATIONS?

Because English-based sign systems do differ from ASL in grammar and in the use of English markers, some Deaf adults do not like them. They feel it is an attempt by hearing persons to impose hearing standards on children who are deaf. In addition, because speech is faster than signs, an individual must be committed to presenting complete English in signs and to make the effort to learn and become fluent.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- Do I believe in the importance of presenting complete English?
- Am I willing to take the time to become fluent?
- What is used in the schools in the area I live?
- What materials are available to help me learn?
- How will I react if I meet negative attitudes from Deaf adults?

TOTAL COMMUNICATION

WHAT IS MEANT BY “TOTAL COMMUNICATION” (TC)?

TC is the title of a philosophy of communication, not a method. TC may involve one or several modes of communication (manual, oral, auditory, written), depending on the particular needs of the child. The original expectation of TC was for teachers to use the communication method(s) most appropriate for a child at a particular stage of development. Therefore, there would be situations when spoken communication would be appropriate, other situations where signing might be appropriate, others that call for written communication, and still others where **simultaneous communication** might work best.

WHAT ARE THE PRINCIPLES OF TC?

TC is meant to be the bridge that allows a crossover from an oral-only philosophy to a philosophy that embraces sign language.

WHO CAN USE THIS OPTION?

TC may be used by families and educators. Since over 90% of parents of children who are hard of hearing are hearing themselves, many believe that TC is a philosophy that will allow flexibility without eliminating options. By using a total approach of speaking and signing, all members of the family, those who are hearing impaired as well as those who are hearing, have continuous access to the communication occurring in their environment. Teachers may choose to provide TC options in their classrooms, as long as they have the skills necessary to meet all of the children's communication needs.

WHAT ARE THE BENEFITS OF THIS OPTION?

The main benefit of TC is that it can open all avenues and modes of communication for the hard of hearing child. Parents and teachers might be reluctant to choose one mode of communication over another. TC, however, allows a variety of combinations. Research studies have demonstrated the beneficial effects of TC in other areas of a deaf child's development, such as psychosocial, linguistic, and academic. TC is considered beneficial because it allows the child to use the form that is best for him in any given situation.

WHAT ARE THE LIMITATIONS?

One limitation is that it may not be put into practice accurately in some situations. Many students who are deaf are immersed in a form of simultaneous communication that does not match their level of language readiness or ability. In the classroom, TC often becomes a simultaneous practice of combining manual components (signs and fingerspelling) with spoken components used in English word order. Almost all TC education programs combine signing with speech. The very nature of the two modes (spoken and visual) may cause signers/speakers to alter their message to accommodate one or the other mode, compromising between the 2 methods. It may also be impossible for teachers to meet all the communication needs that might be present in a single classroom. Researchers do not agree as to whether a manually coded English system leads to better reading and writing scores.

WHAT ARE QUESTIONS TO ASK BEFORE CHOOSING THIS OPTION?

- Will children in a TC program be able to communicate with members of the Deaf Community?
- Can English be represented fully with sign language?
- If TC is chosen as an option, what kind of signing will be used?
- Can ASL be an option in a TC program?
- Can one talk and sign ASL at the same time without negatively affecting one or the other?

OUR FAMILY'S PERSONAL GOALS FOR OUR CHILD'S LANGUAGE ACCESS:

- ✓ Is it important that our child speak English?
- ✓ Our native/home language?
- ✓ How will our child and family interact with the Deaf community?
- ✓ Do we desire our child to attend school with other deaf and hard of hearing children?
- ✓ Do we desire that our child attend community school or be home schooled?
- ✓ How will our extended family, friends and society communicate with our child?
- ✓ Are there other spoken languages we desire our child to learn?
- ✓ Will our child be in day care? What communication mode will best be able to be followed through in this setting?
- ✓

Use these questions to begin to evaluate your family's personal goals for communication.

Remember, these decisions can be changed, as necessary.

BUILDING CONVERSATIONS

One of the most amazing and important accomplishments of infancy and early childhood is the development of language. When a baby is born with a hearing loss, this process of developing language can be delayed. Such delays can be



prevented or reduced through early detection of hearing loss and intervention. Family members can encourage a baby's language, listening and speech during natural daily routines.

Communication starts the moment your baby is born. As you cuddle your little one, you let the baby know, "I love you. I will keep you safe and warm." The process of learning language starts within healthy relationships in early infancy. Babies and parents make special connections through their own unique ways of communicating.

Experts say that how you connect with your baby

- Helps the baby feels secure
- Helps the baby learn

As you cuddle and play with your deaf or hard of hearing baby, you will find special ways to connect. You will discover lots of tools for starting conversations.... using words, sounds, touches, facial expressions, hugs, silly games - just like with any baby. Have fun with your baby and you will figure it out. This next section gives you some additional ideas for starting early conversations with your baby.

GETTING STARTED

In the early weeks and months of your baby's life, you and your baby will make many discoveries about how to connect. Your animated face and voice will bring consistent smiles from her. Your baby will kick and move her arms to show she is excited to see you. She will look into your eyes, listen to your voice and watch intently as your facial expressions change. These enjoyable social interactions are the first step in your communication journey together. During the first eight months of life, babies are learning how to pay attention to those around them and how to engage in social routines with others. This early social-emotional development is a main building block for communication. Interactions we think of as "baby games" are essential for getting communication started. When babies engage with others, they regularly respond with warmth, smiles and an expectation that "this is going to be fun." This happens as early as three to four months of age and makes parenting a rewarding adventure.

Communication is a lot like a friendly game of volleyball or tennis. The ball goes back and forth between partners. They get into a nice rhythm. They try not to hog the ball. They enjoy each other's company. Getting ready to communicate with your baby is just like this...enjoying each other, getting into a rhythm and taking social turns. Keep in mind that each baby is unique...what delights one will quiet another. Trust your instincts as you work to find a rhythm that is comfortable for you and your baby. The pleasure you two share will give your baby a sense of security and motivate her to learn.



You might be thinking...."what is so special about all of this? Isn't this what moms and dads do with any baby?" You are right. Communication with your deaf or hard of hearing baby will start in much the same way as it does with any baby. The message you want to communicate with your face, voice and body is, "we love you...let's have some fun together."

You can follow some simple rules of thumb as you get started with your wee little one:

- **Watch** closely. What is your baby's mood? Try to get into a rhythm that matches your baby's mood. If the baby fusses, you can respond with a sympathetic face and soothing voices. If she smiles, use an animated face and voice in response.
- **Encourage** the baby to look at your face and listen to you. The baby will be interested in looking at you if you use various facial expressions and play social games that build anticipation. Vary your vocal inflections (like we normally do in baby talk) to encourage the baby to begin to listen to your voice.
- **Enjoy** your baby. Parents tell us that it can be hard to focus on typical baby routines when they are worrying about the hearing loss. Other parents can reassure you that "it's going to be all right." Focusing on this message, you can relax a bit and enjoy your little one.

RESPOND TO YOUR BABY'S COMMUNICATION

How do babies communicate? All babies start to communicate well before they know any words. A baby's smile says, "I'm happy" or "Do that game again!" A baby cries to let us know, "I'm hungry" or "I need a diaper change." Babies coo to say, "I feel good." From the first month on, babies listen and pay attention to important voices around them. They discover their voices and play with sounds in squeals, grunts, coos and gurgles. Around six to ten months of age, babies discover that they can join sounds together to babble strings like "dadada" or "gagaga." When babies are about nine months of age, they start to point or reach. These gestures may mean, "I want that!" or "Look at me!"



Family members can help get the communication game started by following two simple guidelines. You will probably notice that you are already doing this naturally. If you are, just keep it up! Follow the two R's of early communication:

- Recognize your baby's signals. Ask yourselves: "What is my baby trying to say with his or her eyes, face, body or voice?"
- Respond to these signals as communication. Remind yourselves, "Talk about my baby's idea."

Recognizing Signals

You will notice over time that your baby will use a variety of ways to express herself. Several possibilities are listed below. Take time to observe your own baby. How is your baby communicating without words? What do you think the baby means? Is she asking for attention or help? Does she want you to look at what she is looking at? Does she want more of something or want you to stop? Is she trying to share something fun with you? Have you noticed that even her cries have different meanings?

- Gestures
- Vocal sounds
- Body movements (kicking, getting excited)
- Eye gaze
- Reaching
- Scooting
- Cries
- Smiling
- Anticipating (e.g., hears pat-a-cake and waits for game to start)
- Watching
- Touching
- Facial expressions
- Getting mad
- Making happy sounds
- Vocal protests or whines

Responding to Signals

So, we have reviewed some common signals to watch for and recognize. Remember to **Look** for anything—a facial expression, eye contact, or a movement that might have meaning for you. Now step two is to **Respond** - when you give a response to your baby's signals, you encourage the baby to communicate more, and you let the baby know, "I heard you!" Every time that you respond to a signal, your baby realizes that that gesture, or vocalization, or facial expression made you understand. Your baby will try to communicate that way again.



Every time that you respond, you are demonstrating that conversations have two sides, and that both partners get a turn (like that volleyball game!). Babies love to communicate. Because they do not always hear us, babies who are hard of hearing or deaf may need us to respond very clearly.

- o If your hard of hearing baby is just getting used to hearing aids, you want to stay close, use a pleasant but clear voice, and talk about the baby's interests and signals.
- o If your family will be using a form of sign language, you want to stay in the baby's line of vision, look at what the baby looks at, match the baby's facial expression, and use simple signs and gestures.

The most important point at the beginning is to be sure that your baby knows that you responded. This will help your baby begin to predict that you will respond. That makes conversations exciting for both of you. The words will come in time.

Follow Your Child's Lead

You want to respond to your baby's communication, but you aren't sure what kind of response to make. The best response follows your child's lead.

Babies and adults are sometimes interested in different things. A mother wants to give her baby a juice cup and talk about drinking, but the baby may at first be fascinated by the condensation running down the outside of the cup. "Wet. Your cup is wet," or "The drop is going down, down, down," is closer to the baby's thought than "Drink your juice," or "This is a cup."

Babies are curious. They are constantly exploring their world. When we try to get their attention to talk about our own ideas, we are taking them away from their interests. They may even be confused if they are thinking about one idea, and getting communication about a different one!

Babies like to communicate about their interests. We don't want to do all of the communicating - that would be like "hogging the ball." Instead, when we see what a baby is attending to, and communicate about that, we teach the baby to start a conversation with us, and learn more about that very interesting drop of water.

One way to be sure that you and your baby are on the same wavelength is to establish joint attention. If your baby points to something, you point, too, before you try to add to the communication. If your baby looks at something and laughs, you look and laugh. If your baby vocalizes at a teddy bear, you do it, too. Then you can add a language turn. You let your actions say, "Your idea was interesting to both of us."

Example #1

This baby touches her wet high chair tray after it is wiped off. How might her mother respond?

The mother might touch the tray and then say, "It's wet." (providing feedback). The mother shows the baby that she shares the baby's idea, and then talks directly about feeling the tray.



Example #2

This eight-month-old baby is playing with a toy and she pushes the swing while vocalizing. How might her mother respond?

- a. Look at the swing with her daughter (joint attention), and
- b. Say, "swinging" (following her lead).



This mom should look at what her daughter looks at (joint attention) and talk about her baby's interest. It is as simple as that.

Talk About What Interests Your Baby

How does your baby let you know what is interesting? Usually, babies look at, touch, grasp, listen to and chew on objects they like. They try to reach interesting objects, or light beams, or other babies. They laugh at unexpected actions and faces. They pay attention to what is interesting and new.

We know all about those things, but for babies, they are new and exciting. When you talk or sign about your baby's experiences while they are happening, then your baby will pay attention to you, too.




Do's	Don'ts
Provide information about the subject. "Airplane. Up-up-up."	Provide too much information. "That's an airplane. It can fly high in the sky and up in the clouds."
Leave a space for another turn. "Big airplane." Then wait expectantly for your baby to take a turn	Decide what the baby's turn will be. "Can you say, 'up'? Let's say, 'up.'"
Support the child's topic.(baby reaches for a rattle) "Want your rattle?" (baby giggles in response to a game) - This signals mom or dad to play more.	Change the subject.(baby reaches for the rattle) "Look...Here's a truck."
Encourage turns .(baby laughs at being jumped) "Jump again?"	Take too many turns ."You like to jump. Want to jump again? Say jump. Say it again. Want to jump?"

Comment on Objects, Actions and Problems

You are the one who has the words for your baby's interests and curiosity. Now that you have become an expert conversationalist and a mind reader, it is time to become a tour guide.

You do get to take conversational turns, too. Your turns are responsive, but they add information. You know where the important, exciting objects, actions and problems are, and you know how to communicate about them. When you play with your baby, you can point out these features. This is called parallel talk.



You can give your baby a play by play of what is happening in the world. Remember, though, not to hog the turns or forget what your baby is attending to. If you play with your baby, you do it in steps. Different steps call for different parallel talk. For example, when you blow bubbles, you might guide him through these steps:

	Find the stick in the bubble bottle.	"Where is it?" "Euw! Sticky!" "There it is."
	Get ready to blow!	"Ready?" "Blow!"
	See bubbles everywhere, floating and popping.	"Up, up." "Pop, pop, pop!" "All gone."
	Feel wet circles everywhere.	"Wet table. Feels wet."

Some of the other activities you guide your baby through could be changing diapers, dressing, eating or getting ready to go in the car. Each of these activities happens in steps, and every one of those steps can become a conversation. What does your baby attend to during changing? It could be the stinky diaper, but it could be the mobile of birds that you hung over the changing table or crib. When you have your coats on and open the door, does your baby notice the cold air, or the keys you are ready to use?

Example

Look at the baby in each picture. Think about what responses might expand the baby's idea. Look on the right to see some examples of parallel talk. These comments could expand the idea while sharing the baby's interest and attention.

baby's action	possible responses
 <p data-bbox="399 842 748 877">Baby picking up cereal from tray.</p>	<p data-bbox="818 674 911 701">"Yum!"</p> <p data-bbox="818 726 1052 753">"Mmmm....good."</p>
 <p data-bbox="399 1199 732 1234">Putting one in mouth-big smile.</p>	<p data-bbox="818 1031 1045 1058">"You like cereal."</p> <p data-bbox="818 1083 1036 1110">"In your mouth!"</p>
 <p data-bbox="456 1545 667 1581">Reaching for more.</p>	<p data-bbox="818 1388 1019 1415">"More cereal?"</p> <p data-bbox="818 1440 1149 1467">"Find more for mommy."</p>

Support taking turns, and stretch to expand communication

Part of communication is showing that your partner's ideas are important to you. You may want to continue a conversation by encouraging your baby to take another turn. You may not get the message the first time. You may not immediately think of a way to respond. You may want to add something to your response to let your baby know you are interested and approving.

Tiny babies make lots of funny sounds. It is not always clear how to answer. As a parent, you have many ways of showing your baby approval and support.

- You can keep your eyes on your baby while the two of you communicate.
- You can smile and nod.
- You can let your face show the same feeling that your baby is showing.
- You can add small words, such as "yes," or "okay" to your response.
- You can wait expectantly for more communication



This baby really likes to babble. Her mom encourages her by smiling, looking and making positive comments. They are having fun with communication.

Babies and toddlers are not always easy to understand. When they begin to say words (often around 12 months of age), their early attempts can change a lot. Toddlers use jargon - a mix of jibberish and a word attempt or two. All babies are unclear at times. Their parents must become good meaning detectives!

When this little girl "talks" on the phone, she is producing jargon. It sounds like she is talking, but the words are hard to understand. The mother shows interest, and then picks up on the one word she follows (baby). She says, "Oh, did you see the baby?" Then she invites her toddler to go back to the conversation, "Say hello to grandma."



Keep it short and simple

Having a conversation with a baby is different than having a conversation with an adult or an older child. When we talk with any young child, we make our face and our voice expressive, we try to say interesting things, and we use short, simple phrases and sentences. We repeat a lot, because we know that young children are not just trying to understand what we tell them, they are also trying to learn about the language we are using. Babies who are deaf or hard of hearing are trying to accomplish those same jobs. Because they have to pay close attention to get a message, they need many, many opportunities. Because the job of acquiring language is complicated, our messages need to be short and simple.

You have practiced responding to signals, commenting on your child's interests, following your baby's lead, and guiding conversations into new and exciting worlds. Every time you use one of these skills, you will also need to practice keeping your conversational turn short and simple.

Some people call the short, animated phrases we use with babies as "baby talk." Some people wonder if they should use baby talk. Rest assured that the changes we make in our voices and speech around babies serves an important purpose. The "sing song" that we use with babies has been called "motherese" or "parentese." It actually helps little ones figure out the complicated language they hear around them. So go right ahead and make your voice interesting (with lots of pitch variation) and keep your phrases short.

Here are some examples of parent conversation turns that are just right, or just a little bit too much:

Short and simple:	Maybe too much for right now:
Big bite!	You ate a big bite and your mouth is full!
Time to go night-night.	Brush your teeth and then go to bed.
That's my sock.	This is mommy's sock and this is your sock.
Mmmmm, good cereal.	That cereal tastes really yummy

Here are some phrases parents might use with their babies. Both of them respond to a signal. One of them is a little too long. Which one do you think is short and simple?

Your baby fusses and pushes a toy away.

A. "No more toy? Ok"

Or

B. "You don't want this toy anymore. Let's find something else for you to look at."



Visual motherese (for signing families)

Perhaps your family has made a decision to use sign language with your baby. When educators explain how hearing parents talk with their babies, you need to know how to use signing in the same way.



Researchers have found that adults automatically change their speech in similar ways when they talk to children. They do not talk to children in the same way they talk to other adults. This adult-to-child talk includes the use of short, simple phrases and changes in the pitch of their voice (called motherese above). These changes make it easier for the child to learn language.

Deaf children may barely hear the pitch changes that parents put in their voices, but you can put the same important changes into your signs, your faces, and your bodies. When people ask questions, for example, the pitch of the voice goes up at the end of a yes-no question, and down at the end of a question starting with words like Where, When, Who, What, How or Why (a WH question). When we sign, our eyebrows and bodies replace pitch. The eyebrows go up for a yes-no question; they furrow, or go down for the WH question, as our bodies lean slightly forward. This part of signing is called facial grammar.

Hearing babies know when their parents are happy, worried, angry, or excited from their voices, even when the baby cannot see the parent's face. Your deaf baby needs to see your facial expression and your body movements to get the same information. Are you smiling, and letting your signs flow? Are you frowning and signing sharp, emphatic signs as you run to cover the electric outlet? Are you pretending to cry as you see a sad character in a story?

Your Early Intervention Specialist can help you with your language and literacy goals for your child.

GETTING READY FOR SCHOOL



Even though your baby is just beginning to grow and develop communication, sometimes you can't help thinking to yourself, "I know it's a long time in the future, but I still wonder about what is going to happen when my baby goes to school. Later on, where will my child go to school? Will my child be able to keep up with other children? How can I get my child ready now for reading, writing, and arithmetic later on? In this section, you can learn how you can help prepare your baby for the experience of school without neglecting the other, important, work of early childhood.

Early Preparation for Later School Experience

Some early school skills are easy to teach. Your child may be saying or signing the alphabet, counting, even recognizing some words by age 3 or 4. However, letters and numbers are only building blocks. Unless a child learns how to build a wall, a house, a sidewalk, or a school with those blocks, they will not be very useful. We say that a child who can count, name colors and shapes, and sing the alphabet song, but who has trouble with language and problem solving, has developed splinter skills.



To really prepare your child for school, you also want to provide other learning opportunities including language experiences, hands on experiences and print experiences:

Language Experience

Language is your first priority. No one learns reading without understanding the stories, no matter how well he knows the alphabet. No one understands mathematics without understanding the story problems, no matter how many numerals he can write. Social studies, science, even the rules of the game in P.E. are all very language based, and to fully participate in any classroom, your child needs to be able to communicate meaningfully on an academic level, which is different from conversation.

The language experiences that lead the 2 year olds to academic language later on come from following their leads and labeling their discoveries. Don't try to "teach concepts" beyond their cognitive level. If a child experiences all of the important parts of early development, then the next stage will have a good base. Be sure to:

- mark the passing of time (wait, now it's time, after your nap),
- spatial concepts (look inside, all over the floor! Eat in your highchair),

- seriation (That's BIG! Look how tiny! You have more),
- classification (Yes, that's a car, and that's a car, too. Look, I have your blue shirt and your red shirt), and
- causality (Uh-oh, I dropped it and it broke! Light on, light off).

Do it when they are attempting to call your attention to these aspects, or when the time is appropriate. You don't need to sit down and think, "Now how can I get seriation into my life today?" Rather, in any situation, think, "What does she/he seem to be noticing? How can I label the concept?"

Hands On Experience

Experience is the basis for later school learning. We learn to read, write, and figure about things, actions, and relationships that we have experienced. To learn well in school later, your child needs to simply interact with a rich environment now. Does he have safe plastic containers of varied sizes, with and without lids, spouts and handles, to pour out of and into and squirt with in the bathtub or wading pool? Does she sit in the shopping cart and see the food come off the shelf, go through the cash register line, into bags, home, and onto shelves in cupboards and refrigerator? Do you go for walks and take time to notice leaves emerging or falling, or bugs, or interesting animals in yards? In any experience, no matter how ordinary, notice what she is attending to, and attend to it also, with body language, words, and actions. You are telling him, "Noticing is important. What interests you is worth learning about. *Curiosity is a virtue.*" Of course, by creating the opportunities, and taking a turn at calling attention to things yourselves, you will open up her horizons even more. Just don't have all the ideas. She needs to have many of her own.

Print Experience

Awareness of interaction with print in the environment is vital.

Don't assume that your child knows that you read, not only books, but directions, signs, logos, recipes, labels, newspapers, magazines, closed captions (don't wait until he starts school to have that available), and telephone directories.

Communicate what you are doing overtly-

"I need to look up the number in the phone book."

Get out the book in his line of vision.

"It's heavy." "There are a lot of names."

"Here it is!" "I hope that I remember the number: 555-9678, 555-9678."





THE LITERATE HOME ENVIRONMENT

For preschoolers, literacy is many things, not just reading and writing. Preschoolers need to know that people read and write the print that is all around them. They need to know that there are reasons to read, write, and use mathematics. We need to help them understand and enjoy stories, and encourage them to experiment with reading and writing. We should let them know that letters, numbers, words, sentences, and punctuation marks exist, and know their names. Most important, we need to build on their curiosity to help them want to know what people are reading, writing, and calculating.

Think about these questions: where is the literacy potential in my home environment? How can I help my child notice my reading, writing and math and understand the purpose? How can I increase the amount of interaction about print, numbers, and stories between my child and me? How can I increase the amount of functional print available in the environment?

Where is the literacy potential in my home environment?

You might sit down and think about the ways that you use literacy or could use literacy already in your home. Your list might look like this:

- **Grocery Lists:** I look in the cupboard and refrigerator and write things down, talking (singing) to myself as I go, or I empty the carton of milk and write MILK on the list on the refrigerator door.
- **Family Memos:** There is a white board by the door or the telephone. Before I leave the house, I usually leave a message for my spouse or an older child, saying, "Gone to store. Be right back. Love you."
- **Children's Books:** My older children bring me a book every night before bed and ask me to read it to them. Sometimes we read a chapter a night. Sometimes, it is the same book over and over.
- **Accessible Paper:** There is a drawer with all kinds of paper (newsprint, old blank checks, lined paper, ends of spiral notebooks) and writing utensils (pencils, ball point pens, crayons, gel pens) for experimenting with drawing and writing any time. Sometimes we turn the TV off and suggest that the children read or draw or write.

How can I help my child notice my reading, writing and math and understand the purpose?

You have your list of literacy in your home. Now you have to decide, "how can I call my child's attention to all the reading and writing and calculating that happens every day? Add some more items to the list.

- I can "think out loud" when I use reading, writing and math in my daily life: "This cereal box is almost empty. I will write 'cereal' on the list." "Look how much this new cereal costs. Do I have enough money?"
- I can talk to someone else about what I am reading, writing, or calculating: (to an older child) [Mom]"The paper says there will be snow. Where is your winter coat?" [Child]"I put it in the closet. I'll get it."
- I can involve my deaf or hard of hearing child in the conversation: "This letter is for Daddy. Give it to Daddy."
- I can involve my deaf or hard of hearing child in the act of reading or writing or using numbers. "Let's write Daddy a note. 'Mommy and Evan are at the store.' You write your name." "There's the pop machine. It costs 55 cents. You put in the money. See, the machine says how much you put in. Now it is 55. You can push the button."

How can I increase the amount of interaction about print, numbers, and stories between my child and me

On another page, put a list of things that you could do to increase the print in the environment or the ways that you call your child's attention to it. One easy entry could read: "I can follow all the conversation suggestions in the "Building Conversations" section of this manual.

You can also include ideas like these:

"I can increase the amount of functional print available in the environment:

- if I use closed captioning for television shows and movies when my child is in the room,
- if the family writes and signs group birthday cards, valentines, and holiday greetings, and
- if I label drawers, cupboards and closets with pictures and category names for their contents (e.g. dishes, glasses, coats and boots, Susie's clothes, Mommy's clothes, pots and pans).

"I can increase my child's attention to literacy if I pay attention when my child expresses even nonverbal interest in print or numbers in the environment, asking me to read them, name them or tell what they mean."

"I can model the use of a TDD/TTY for telephone conversations."

"I can read out loud the letters and cards that arrive from friends and family members."

Sharing your goals with others

The more people who can give your child the same experiences, the faster your child will develop those language and problem solving skills needed to make school a pleasant experience. First, of course, you want to share your child's goals with other family members, including anyone outside the home who sees your child often. In addition, if your child goes to preschool, daycare, Sunday school, or playgroup, you can share your goals with the caretakers and teachers in these environments. In return, they can tell you about the chances for emerging literacy they provide in their settings.



Family members are usually around to talk with, but other adults may be harder to find. A lot of parents send notebooks with their children. We can use these notebooks for a lot more than "John has a cough today," or "Jane has her teddy bear in her backpack." Here are some ideas:

When something exciting happens at home, sit down with your child and draw a picture (stick figures are fine) and collaborate on a few short sentences to write. Send the notebook to school and prime the other adult to ask about the experience. A preschool teacher might sit down and help the child reproduce a personal page of "drawing" and "writing" about the excitement that she can share with the other children or put on a bulletin board.

When your child seems interested in a new kind of print, write it in the communication notebook. "Jane noticed that the logo on the grocery bag was the same as the sign on the grocery store," or "John said that Java Club has the same letter as his name when we bought coffee today." Encourage teachers and caretakers to share similar anecdotes.

When the information in the communication notebook includes personal, safety, or health items, take time to sit down and say, "Ms. Haines says you were dry all day!" or "Look, here it says you fell down. Can I see your band-aid? Does your cut hurt?" Children begin to take it for granted that information is conveyed through print; they will begin to give their notebooks to adults with confidence that the adult will understand. They may also begin to tell an adult, "Write that down for Mom."

More Ideas for Increasing Literacy Skills with Your Deaf or Hard of Hearing Toddler

- Any activity that requires taking turns, remembering, sharing, or sorting while communicating is a good pre-reading activity. If you are unpacking groceries, say and sign, "Put all the cans on the table."
- Talk and sign to your toddler all the time! – cleaning, gardening, sewing, and setting the table – any activity can be a time to share communication.
- Let your child play with alphabet blocks and magnetic letters. Make your own letters, numbers, and words with crayons, pencils and paper.
- Point to an object and name what you see. Talk about it. If you are sorting laundry, say "This is a towel."
- Offer your child choices. Choices encourage your toddler to communicate and stimulate thinking. Point to some books. Say "Which one?" Let your child pick the story he likes best.
- Before you start any activity, get rid of distractions.





Literacy Checklist

Every day, chances to encourage literacy happen. When we remember to write them down, we can share them with others and use them as reminders for other days. Here is a way to keep track of a few of the literacy opportunities that happen in a day.

What am I Doing at Home to Encourage Literacy?

What were we doing?	What did I do that encouraged literacy awareness?	What did my child do then?

TERMS &**DEFINITIONS:**

- **Terms Related to Communication**
- **Terms Related to Hearing**
- **Terms Related to Community and Services**

ACOUSTICS

Pertaining to sound, the sense of hearing, or the science of sound. Often used to refer to the quality of the sound environment.

ACQUIRED HEARING LOSS

A hearing loss that is not present at birth. Can be due to illness, risk factors, or exposure to noise. (see *"First Steps-Newborn Screening"*) Also known as "late onset hearing loss".

ADVOCATE

A person who stands up for the rights of another person(s).

AMBIENT NOISE

Background noise, which competes with the main speech signal.

AMERICANS WITH DISABILITIES ACT (ADA)

This federal law was written to provide certain rights to people with disabilities. It applies to children as well. This law bans discrimination based on disability in the areas of public accommodations, state and local government services, employment, transportation and telecommunications. All public schools must comply with the ADA.

AMPLIFICATION

The use of hearing aids and other electronic devices to increase the loudness of a sound so that it may be more easily received.

ASSISTIVE LISTENING DEVICES (ALD)

Amplification systems designed specifically to help people hear better in a variety of difficult listening situations.

AUDIOGRAM

A graph on which a person's ability to hear different pitches (frequencies) at different volumes (intensities) of sound is recorded.

AUDIOLOGIC ASSESSMENT

A comprehensive evaluation of hearing which identifies the type and degree of hearing loss. The test can also assess how well a child is hearing with amplification.

AUDIOLOGIST

A person who holds a masters or doctoral degree with special training in identification, measurement, and rehabilitation of persons with a hearing loss.

AUDIOLOGY	The science concerned with the sense of hearing.
AUDITORY BRAINSTEM RESPONSE (ABR)	A non-invasive test that measures auditory responses at the level of the brainstem in response to auditory stimuli. This test can indicate whether or not sound is being detected, even in an infant. This test may also be referred to as BAER or BSER.
AURAL HABILITATION	Training designed to help a person with hearing loss to make productive use of residual hearing. Sometimes includes training in speech reading. (AUDITORY TRAINING)
BILATERAL HEARING LOSS	Hearing loss in both ears.
BILINGUAL/BICULTURAL	Being fluent in two languages and membership in two cultures, such as hearing (spoken language) and the Deaf culture (American Sign Language).
BINAURAL AMPLIFICATION	Hearing aids worn on both ears.
BONE CONDUCTION	Sound received through the bones of the skull.
CHILD DEVELOPMENT	The usual patterns in which a child grows and develops.
CLOSED CAPTIONED	Printed conversations for deaf or hard of hearing to read on a television or movie theatre screen.
COCHLEAR IMPLANT	An electronic device surgically implanted to stimulate nerve endings in the inner ear (cochlea) in order to receive and process sounds. It transmits auditory information directly to the brain, bypassing damaged hair cells in the cochlea.
COGNITIVE	Refers to the ability to think, learn, and remember.
CONDITIONED PLAY AUDIOMETRY (CPA)	Generally used when the child is at least 18 months old. The audiologist helps the child understand the rules for playing a game where the child listens for a sound and then performs a task (game).

CONDUCTIVE HEARING LOSS	Hearing loss due to failure of sound waves to reach the inner ear through the normal air conduction channels of the outer and middle ear. In children, conductive loss is often temporary or medically correctable, and is most often associated with Otitis Media.
CONGENITAL HEARING LOSS	Hearing loss present at birth or associated with the birth process, or which develops in the first few days of life.
DEAF	Generally the term “deaf” refers to those who cannot hear well enough to rely on their hearing and use it as a means of processing information. The uppercase “Deaf” is used when referring to a particular group of deaf people who share a language, American Sign Language, and a culture.
DEAF COMMUNITY	A group of people who share common interest and a common heritage. Their mode of communication is American Sign Language (ASL). The Deaf community in the United States may have a wide range of perspectives on issues, but emphasis remains on Deafness as a positive state of being. Levels of deafness vary in individuals who consider themselves part of this community.
DEAF CULTURE	Refers to a group of deaf people who share the language of ASL, who use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. It is transmitted across generations, just like other cultures.
DECIBEL (dB)	The unit of measurement for the loudness of a sound. The higher the dB, the louder the sounds and the worse the hearing loss.
DEVELOPMENTAL DELAY, (DISABILITY)	Any physical, mental, visual, or hearing loss that limits a person in the activities of daily living
EARMOLD	A custom-made piece which fits into the outer ear and connects to a hearing aid.
ELIGIBILITY	A child must be determined eligible for special education services, based on specific disabilities or developmental delay. Children with hearing loss are eligible for early intervention services.
ENT	A medical doctor who specializes in the ears, nose and throat. Sometimes referred to as an otolaryngologist or otologist.

ENVIRONMENTAL SOUNDS	All sounds that occur in a given environment such as the sound of a train, plane, car, running water, etc.
FAMILY DYNAMICS	Interactions within and surrounding the family.
FINGERSPELLING	An organized system of hand shapes, which represent the letters of the alphabet, generally used to supplement sign systems.
FM SYSTEM	An assistive listening device worn by the speaker to transmit the speaker's voice directly via radio waves to a receiver worn by the listener. The device reduces the problem of background noise interference and the problem of distance between speaker and listener.
FREQUENCY	The number of vibrations per second of a sound. Frequency, expressed in Hertz (Hz), determines the pitch of the sound.
GAIN	The amount of amplification provided. For example, a child with unaided hearing at 70 dB who, when amplified hears at 30 dB, is experiencing a gain of 40 dB.
GENETIC COUNSELING	Genetic counseling includes recurrence risk information for individuals with hearing loss and their families.
HARD OF HEARING	A person who has a hearing loss that can be mild, moderate, or severe.
HEARING AGE/ AIDED AGE	Age measured from the time the child begins wearing hearing aids or a cochlear implant consistently.
HEARING AID	An electronic device that conducts and amplifies sound to the ear.
HEARING IMPAIRED	This term is sometimes used to refer to any person with a hearing loss whether they are deaf or hard of hearing. This term is not recommended because most people who are deaf do not consider that they are hearing impaired.
HEARING SCREENING	Testing of the ability to hear selected frequencies at intensities above normal hearing. The purpose is to identify individuals with potential hearing loss and refer them for further testing.
HUGGIES	The brand name of a plastic-ringed device designed to "hug" the hearing aid to the ear. Popular for infants and toddlers whose ears

may be too small to hold the hearing aid snugly in place.

I .D.E.A.	The Individuals with Disabilities Education Act, <u>Public Law 105-17</u> . Requires services for children from birth to 21 years of age with disabilities.
I NCLUSION	Refers to the concept that students with disabilities should be integrated and included to the maximum extent possible with their (typically developing) peers in the educational setting.
I NDIVIDUALIZED EDUCATION PLAN (IEP)	A written plan, consisting of specific educational goals and objectives, developed by an educational team, including the parents, to meet the educational needs of the child (ages 3-21).
I NDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)	A written plan for serving each disabled child, age 0 to 3, which outlines the strengths and needs of the child and family, how the services will be provided, and by whom.
I NFANT TODDLER PROGRAM	A statewide community based program which identifies infants and toddlers who have a developmental delay or disability, or conditions which lead to such a delay or disability; and which provides early intervention services to meet the individualized needs of those children and their families.
I NTENSITY	The loudness of a sound, measured in decibels (dB)
I NTERPRETER	A person who facilitates communication between persons who are hearing and those who are deaf or hard of hearing, Transliterator.
I NTONATION	The aspect of speech made up of changes in stress and pitch in the voice.
LEAST RESTRICTIVE ENVIRONMENT	A basic principle of Public Law 105-17 (IDEA), which requires public agencies to establish procedures to ensure that to the maximum extent appropriate, children with disabilities are educated with children who are not disabled.
MIXED HEARING LOSS	A combination of conductive and sensorineural hearing losses.
MONAURAL AMPLIFICATION	The use of one hearing aid instead of two.
MULTI -DISCIPLINARY EVALUATION	Two or more qualified professionals evaluate the child's development to determine if there are any delays or conditions that would indicate the need for early intervention or special services.

ORAL	An unspecific term that is sometimes used when referring to individuals with a hearing loss who talk, but do not necessarily use sign language.
OTITIS MEDIA	A middle ear infection. Children with recurring episodes may experience fluctuating hearing loss and may be at risk for speech language delays. Fluid can be present with or without infections and may cause temporary hearing loss, which can evolve into permanent loss.
OTOACOUSTIC EMISSIONS (OAE)	An audiologic test that verifies cochlear activity often used in screening infants for hearing loss.
OTOLARYNGOLOGIST	See: ENT
OTOLOGIST	A physician who specializes in medical problems of the ear.
PART B	The section of Public Law 105-17 (IDEA) that refers to special education services available to eligible children aged 3 through 21 in the public schools.
PART C	The section of Public Law 105-17 (IDEA) that refers to early intervention services available to eligible children from birth through two years of age and their families.
PEDIATRIC AUDIOLOGIST	An Audiologist specifically trained in identification and treatment of hearing loss in infants and children.
POST-LINGUAL HEARING LOSS	Refers to hearing loss acquired after learning a first language.
PRE-LINGUAL HEARING LOSS	Hearing loss that is present at birth or occurred prior to the development of speech and language.
PROGRESSIVE HEARING LOSS	A hearing loss that increases over time.
PSYCHOSOCIAL	Pertaining to, or involving both social and emotional issues.

REAL-EAR MEASUREMENT	An audiological test that measures the actual output of the hearing aid in the ear canal. It assesses how effectively sound is actually being amplified by the hearing aids in the ear.
REFERRAL	Referring a child to the different agencies that will provide services.
RELAY SERVICES	Relay Service/Relay Network – A service which involves an operator “relaying” conversation between a TDD/TTY user (generally a person with a hearing loss and/or a speech disorder) and a hearing/speaking individual using an ordinary, non-adapted phone.
RESIDUAL HEARING	The amount of usable hearing that a person with hearing loss has.
SENSORINEURAL	A type of hearing loss (usually irreversible) caused by damage that occurs to the inner ear (cochlea) and/or the nerve of hearing.
SPEECH AWARENESS THRESHOLD	This is the faintest level at which an individual detects speech 50% of the time.
SPEECH BANANA	The area on an audiogram where most conversational sounds of spoken language occur (SPEECH ZONE).
SPEECH INTELLIGIBILITY	The ability to be understood when using speech.
SPEECH RECEPTION THRESHOLD	The faintest level at which an individual identifies 50% of the simple spoken words presented.
SPEECH-LANGUAGE PATHOLOGIST	A professional who works with individuals who have specific needs in the areas of speech and language.
SPEECHREADING (LIPREADING)	The understanding of a speaker’s words by watching lips and facial expressions.
SYNTAX	The way in which words are put together to form sentences, clauses, and phrases.
TACTILE AIDS	A type of assistive communication device that emits a vibration or “tactile” signal to indicate the presence of sound(s). It is worn on the body and triggers the sense of touch to draw attention to information that cannot be heard by the individual with hearing loss.

**TELECOMMUNICATION
DEVICES (TTY/TDD))**

(TTY – Teletypewriter, TDD – Telecommunication Device for the Deaf, TT – Text telephones.)

Originally and often still called TTY's, these electronic devices allow the deaf and hard of hearing to communicate using a keyboard to type conversation and a visual display to read what is being typed.

TRANSLITERATOR

See: Interpreter

TYMPANOGRAM

A pressure or “impedance” test that tells how the ear canal, eardrum, eustachian tube, and middle ear bones are working. It is not a hearing test.

**UNILATERAL HEARING
LOSS**

A hearing loss in one ear.

**VISUAL REINFORCEMENT
AUDIOMETRY (VRA)**

A method of assessment in which the child is conditioned to look at a toy that lights each time he or she hears a sound.

WHERE TO FIND THE INFORMATION YOU NEED



There are many ways to find information that will educate you about your child's hearing loss, as well as how to cope with that loss. This section contains contact information for some of the many organizations and companies that may be of help to you.

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NOTES:



IDAHO RESOURCES:

Idaho Council for the Deaf and Hard of Hearing

1720 Westgate Dr. Suite A

Boise, ID 83704

(208) 334-0879 (voice)

(800) 433-1323 (voice)

(208) 334-0803 (TTY)

(800) 433-1361 (TTY)

www2.state.id.us/cdhh

e-mail: cooperp@idhw.state.id.us

Idaho Sound Beginnings

Early Hearing Detection & Intervention

(208) 334-0829

(800) 433-1323

www.infanthearing.org

www2.state.id.us/cdhh

Idaho School for the Deaf and Blind

1450 Main St.

Gooding, ID 83330

(208) 934-4457 V/TTY

FAX (208) 934-8352

www.isdb.state.id.us

Deaf Connection

Provides resources and support in the Treasure Valley for parents, friends, and family of children who are deaf and hard of hearing.

P.O. Box 140245

Boise, ID 83714

(208) 938-9802 V/TTY

Idaho Hands & Voices

Statewide parent-to-parent support organization for families with infants or children with a hearing loss.

Boise, ID 83704

Idaho Hands & Voices

(800) 433-1323 V

(800) 433-1361 TTY

(208) 334-0879 V

(208) 334-0803 TTY

Idaho Care Line

Provides referrals for health and human services around the state.

(Se habla español)

1-800-926-2588

(208) 332-7205 TDD

www.idahochild.org

Idaho Parents Unlimited, Inc.

Statewide organization providing support, information and technical assistance to parents of children and youth with disabilities.

600 N. Curtis Rd. Suite 100 Boise, ID 83706

(800) 242-IPUL (4785)

IPUL@rmci.net

www.ipulidaho.org

Idaho Project for Children and Youth with Deaf-Blindness

Center on Disabilities and Human Development

University of Idaho, Boise Center

800 Park Boulevard

Boise, ID 83712

(208) 364-4012

www.ets.uidaho.edu/cdhd

Idaho Assistive Technology Project

129 W. Third St.

Moscow, ID 83843

(208) 885-3573

1-800-432-8324 (Voice & TTY)

www.ets.uidaho.edu/idatech

Idaho Infant Toddler Program

Bureau of Developmental Disabilities
Department of Health and Welfare
PO Box 83720
450 W. State Street
Boise, ID 83720-0036
(208) 334-5514
www.idahochild.org

Contact information for **Infant Toddler Program** regional Child Development Centers is in the following section.

Idaho Department of Education

Bureau of Special Education
PO Box 83720
Boise, ID 83720-0027
(208) 332-6910
www.sde.state.id.us/specialed

Individual School Districts:

State Department of Education
(208) 332-6800

Idaho Vocational Rehabilitation Agency

Division of Vocational Rehabilitation
PO Box 83720
Boise, Id 83720-0096
www.state.id.us/idvr/idvrhome.htm
Regional office information is in the following section.



Idaho Registry of Interpreters for the Deaf

www.idahorid.org

State of Idaho Genetic Services Program

Department of Health and Welfare
Boise, ID
(208) 334-2235 ext. 261

Anne Spencer, MS
Certified Genetic Counselor
2220 Old Penitentiary Rd.
Boise, ID 83712
(208) 334-2235 ext. 258

Assistance League of Boise

Operation: Can You Hear Me?
Activities include: hearing testing of schoolchildren, a hearing aid bank financial assistance to purchase assistive devices, and other hearing related services.
5825 Glenwood,
Garden City, ID, 83714
(208) 377-4327
www.alboise.org

Idaho Speech, Language & Hearing

Association- ISHA
www.idahosha.org

United Cerebral Palsy of Idaho, Inc.

Kathy Griffin, UCP Program Director
5420 W Franklin Road, Suite A
Boise, ID 83705
Phone & TTY (208) 377-8070
Fax (208) 322-7133
Toll Free 888-289-3259
Hours: Monday - Friday
10:00 a.m. - 4:30 p.m.
<http://ucpidaho.ataccess.org/>

[illegible]

Council for the Deaf and Hard of Hearing

Established in 1991, the Idaho Council for the Deaf and Hard of Hearing is a state agency serving people who are deaf or hard of hearing. A nine-member Council governs it. An Executive Director administers all programs and daily operations. The Council's goal is to improve the quality of life for Idahoans who are deaf or hard of hearing by:

- Providing information.
- Serving as an advocate.
- Expanding services for persons who are deaf or hard of hearing.
- Improving access for those persons whom are deaf or hard of hearing.

Our Purpose

To meet the needs of persons, who are deaf or hard of hearing, Chapter 73, Title 67 of the Idaho Code outlines the following responsibilities of the Council:

- ✓ Increase access to employment, educational and social interaction opportunities.
- ✓ Increase awareness of the needs of the deaf and hard of hearing through educational and informational programs.
- ✓ Encourage consultation and cooperation among agencies, departments, and institutions.
- ✓ Determine the extent and availability of services, the need for services and make recommendations for changes.
- ✓ Coordinate, advocate for, and recommend the development of policies and programs that provide full access for the deaf and hard of hearing.

Council Members

By statute there are nine voting members appointed by the Governor. They are:

Member who is deaf and who represents an organization of persons who are deaf

Steven G. Stubbs (1st term)
4229 N. Shamrock (208) 322-4976 TDD
Boise, Idaho 83713

Member who is hard of hearing and who represents an organization of persons who are hard of hearing

John Centa (3rd term) (208) 772 3033 (V)
1190 Progress Drive
Hayden, Idaho 83835

Member who is the parent of a child who is hard of hearing

Mary Reis (3rd term) Co-Chair
1070 Park Meadows Drive (208) 733-1504
Twin Falls, Idaho 83301

Member who is an audiologist

Dr. Ron Schow (5th term)
Box 8116 (208) 282-3811 (TDD)
Idaho State University (208) 282-2199 V
Pocatello, Idaho 83209

Member who is the parent of a child who is deaf

Ellen Van Slyke Thompson (2nd term) Co-Chair
1846 W. Greenhead Drive (208) 888-4850
Meridian, Idaho 83642

Member who is a physician

Dr. Lance W. Coleman (2nd term)
13455 W. Bluebell (208) 939-3969
Boise, Idaho 83704

Member who is deaf

Walter Jastremsky, Jr. (5th term)
906 E. Bannock (208) 336-0419 TTY
Boise, Idaho 83712

Member who is hard of hearing and is over the age of 60

Ms. Lorrain H. Carlson (2nd term)
Box 1238 (208) 939-6979
Eagle, Idaho 83616

Member who is an interpreter

JoAnn Dobecki-Shopbell (2nd term)
764 Academic Drive (208) 734-0426 (V)
Twin Falls, Idaho 83301

Ten non-voting, ex-officio members represent organizations that provide services to persons who are deaf or hard of hearing.

Our Activities

Early Identification: To encourage the early identification of infants and children with hearing loss, the Council will:

- ❖ Work with the Newborn Hearing Screening Consortium to ensure that infants are screened for hearing loss and receive early intervention and follow up services.
- ❖ Work with Idaho's school districts to make hearing screening a reality at certain grade levels in schools.
- ❖ Make sure referrals for treatment are made and accommodations provided.

Community Outreach: The Council takes the following measures to serve the deaf and hard of hearing and to inform the public about their needs:

Education:

- ✓ Equip and supervise Assistive Device Demonstration and Loan Centers in Moscow, Boise, Twin Falls, Idaho Falls and Pocatello
- ✓ Provide information on assistive devices for hearing loss.
- ✓ Provide information on the Americans with Disabilities Act's requirements on communication access and reasonable accommodation.

Prevention:

- ✓ Publicize the facts regarding hearing loss due to extended exposure to loud noises and the need for protection.

Newsletter:

- ✓ Publish free quarterly newsletter to members of the deaf and hard of hearing community, family members, agencies and businesses.

Communication Access:

- ✓ Provide information to public and private businesses regarding the communication access needs of persons with hearing impairments.

Information and Assistance:

- ✓ The Council staff provides statewide information and assistance on issues dealing with persons who are deaf or hard of hearing and provides information to other state, local and national agencies and organizations. Council members provide information to their local areas.

Advocacy: The Council serves as an advocate for persons who are deaf or hard of hearing.

Interpreters: The Council publishes and distributes a Directory of persons working as interpreters. This Directory is also available on line. The Council has developed standards for Educational Interpreters and is part of an interagency consortium to implement a mentoring program for interpreters.

RESOURCE GUIDE FOR AUDIOLOGICAL SERVICES FOR INFANTS AND NEWBORNS

Pediatric Audiology Network ***IDAHO SOUND BEGINNINGS***

The purpose of this guide is to provide you with information about Audiology services in your area. Audiologists are professionals with Masters (M.S., M.A., MCD) or Doctoral degrees (Ph.D., Au.D.) and specialize in hearing care. Audiologists are qualified to diagnose hearing loss and dispense hearing aids.

The information in this guide was obtained from Audiologists in response to a survey sent by Idaho Sound Beginnings. This survey was designed to determine the level of hearing care that each Audiologist is able and willing to provide to pediatric populations. Audiology services include hearing screening, diagnostic testing which goes beyond screening measures (ABR, OAE), tympanometry (middle ear assessment), behavioral testing (visual reinforcement audiometry, conditioned play audiometry), and hearing aid dispensing. (See the section entitled “Audiological Tests” for more information regarding these tests.)

Not all centers or Audiologists provide comprehensive Audiological services. To help you and your Physician determine the best diagnostic center for your child, we have organized the guide into two categories; those centers or Audiologists that provide *Comprehensive Audiological Services*, and those that provide only *Limited Audiological Services* based on information provided solely by the audiologists. Diagnostic centers are listed alphabetically by State and City.

Comprehensive Audiological Services

- ▣ Can test all ages
- ▣ Can perform full range of diagnostic audiology
- ▣ Can select and fit appropriate amplification for all ages

Limited Audiological Services

- ▣ May not have facilities to test all ages
- ▣ Does not perform full range of diagnostic audiology (May not have OAE's or ABR's)
- ▣ May not fit amplification on young children
- ▣ Call the Center or Audiologist for specifics

COMPREHENSIVE SERVICE AUDIOLOGY CENTERS:**BOISE, ID****AUDIOLOGY & HEARING AID CENTER**

Cynthia Olsen, MCD, CCC-A
3320 N. Milwaukee, Suite #125
BOISE, ID 83704
208-658-0238

SOUTHWEST IDAHO ENT

Dean Harmer, Ph.D.
Rebecca Bishop, M.S., CCC-A
900 N. Liberty, #400
BOISE, ID 83704
208-367-7429

IDAHO ELKS REHABILITATION HOSPITAL

Michael Sturmak, M.S., CCC-A
Clair Ketchum, M.A., CCC-A
Lynn Reese, M.S., CCC-A
Shannon Gower, M.S., CCC-A
124 W. State Street
BOISE, ID 83702
208-344-4843

TREASURE VALLEY HEARING AIDS

Curtis Whitcomb, M.S., CCC-A
1084 N. Cole Rd.
BOISE, ID 83704
208-672-9201

IDAHO FALLS, ID**THE HEARING CLINIC**

Gerald Mill, Ph.D.
1662 John Adams Pkwy
IDAHO FALLS, ID 83401
208-529-1514

MERIDIAN, ID**IDAHO ELKS REHABILITATION HOSPITAL**

Kathleen Wachtler, Au.D., CCC-A
Deborah Kernan, Au.D., CCC-A
Alicia Crofts, M.S., CCC-A
520 S. Eagle Road, #1225
MERIDIAN, ID 83642
208-888-0026

NAMPA, ID**IDAHO ELKS REHABILITATION HOSPITAL**

Rebecca Pixley, M.S., CCC-A
212 10th Ave. South
NAMPA, ID 83651
208-461-5615

POCATELLO, ID**IDAHO STATE UNIVERSITY**

Ron Schow, Ph.D.
Mary Whitaker, M.S., CCC-A
Randy Bishop, M.S., CCC-A
Campus Box 8116
POCATELLO, ID 83209
208-282-3495

TWIN FALLS, ID**TWIN FALLS CLINIC & HOSPITAL**

Jay Lloyd, M.S., CCC-A
660 Shoshone St. East
TWIN FALLS, ID 83301
208-733-3700

TRINITY EAR NOSE & THROAT, PC

Joe Seitz, M.S., CCC-A
1330 Filer Avenue East
TWIN FALLS, ID 83303
208-324-4414

COMPREHENSIVE SERVICE AUDIOLOGY CENTERS: (continued)**LOGAN, UTAH**

UTAH STATE UNIVERSITY
Kenneth Curtis, M.S., CCC-A
1000 Old Main Hill
LOGAN, UT 84322
435-797-2670

MISSOULA, MT

FORT MISSOULA HEARING CENTER
Ruth Fugelberg, M.S., CCC-A
2831 Fort Missoula Rd, #300
MISSOULA, MT 59804
406-542-5200

SPOKANE, WASH.

SPOKANE ENT
Kami Fehlig, M.S., CCC-A
217 W. Cataldo
SPOKANE, WA 99164
509-624-2326

WASHINGTON STATE UNIVERSITY
Barbara Peregoy, M.S., CCC-A
Jeff Nye, M.S., CCC-A
310 N. Riverpoint Blvd, Box V
SPOKANE, WA 99202
509-358-7580

LIMITED SERVICE AUDIOLOGY CENTERS:**BOISE, ID**

BOISE SPEECH & HEARING
Brent Bowman, M.S., CCC-A
Brek Stoker, M.S., CCC-A
6700 Emerald Street
BOISE, ID 83704

CALDWELL, ID

**IDAHO ELKS REHABILITATION
HOSPITAL**
Rebecca Pixley, M.S., CCC-A
2615 Cleveland Blvd.
CALDWELL, ID 83605
208-454-6266

CHUBBUCK, ID

THE HEARING ZONE
Kelley Olenick, M.S., CCC-A
Caroline Kerr, M.A., CCC-A
4155 Yellowstone # 1260
CHUBBUCK, ID 83202
208-238-0020

GOODING, ID

IDAHO SCHOOL FOR THE DEAF & BLIND
Gayle Chaney, Au.D., CCC-A
1450 Main Street
GOODING, ID 83330
208-934-4457

IDAHO FALLS, ID

CHILD DEVELOPMENT CENTER
Cate Carpenter, M.S., CCC-A
2475 Leslie Ave.
IDAHO FALLS, ID 83402
208-525-7223

LEWISTON, ID

VALLEY EAR NOSE & THROAT
Richard Young, M.S., CCC-A
330 Warner Drive
LEWISTON, ID 83501
208-743-8930

LIMITED SERVICE AUDIOLOGY CENTERS: (continued)

MOSCOW, ID

VALLEY EAR NOSE & THROAT

Maxine Miller, M.S., CCC-A
619 S. Washington, #301
MOSCOW, ID 83843
208-882-7119

TWIN FALLS, ID

SNAKE RIVER ENT

630 Addison W. #240
TWIN FALLS, ID 83303
208-735-1000

LOGAN, UTAH

BRIDGERLAND AUDIOLOGY & HEARING AIDS

Budge Clinic ENT/Audiology Services
1350 N. 500 E.
LOGAN, UT 84341
435-792-1855

ONTARIO, OREGON

ONTARIO AUDIOLOGY

Christine Wallace, M.S., CCC-A
1159 SW 4th Ave.
ONTARIO, OR 97914
541-881-0970

SANDPOINT, ID

AUDIOLOGY RESEARCH ASSOCIATES

Yancie Kidd, M.S., CCC-A
Clarissa Larson, M.S., CCC-A
420 North 2nd
SANDPOINT, ID 83864
208-255-4389

MISSOULA, MONTANA

WESTERN MONTANA CLINIC

Lynn Harris, Au.D. CCC-SP/A
Box 7609
MISSOULA, MT 59807
406-721-5600

FAMILY HEARING CLINIC

Robert Stevenson, M.S., CCC-A
293 S. Main St.
LOGAN, UT 84321
435-753-4133

PULLMAN, WASHINGTON

AUDIOLOGICAL SERVICES

Sharon Richardson, M.S., CCC-A
825 EW Bishop Blvd.
PULLMAN, WA 99162
509-332-8843

ASSISTIVE DEVICE DEMONSTRATION AND LOAN CENTERS

A COMMUNITY PARTNERSHIP WITH
UNITED CEREBRAL PALSY (UCP)
DISABILITY ACTION CENTER (DAC)
LIVING INDEPENDENTLY FOR EVERYONE (LIFE)
IDAHO STATE UNIVERSITY
AND LIVING INDEPENDENCE NETWORK CORP. (LINC)

The Idaho Council for the Deaf and Hard of Hearing has equipped five Assistive Device Demonstration and Loan Centers in Idaho. Any person, of any age, can visit to learn more about devices. These centers also have applications available for people to apply for assistance to purchase an assistive device. This subsidy program requires that the applicant pay part of the cost of the equipment. The amount they must pay depends on their income.

Many deaf or hard of hearing people, and/or relatives, are unaware of the devices currently available. The demonstration centers allow individuals to try out different devices and borrow equipment on a short-term basis for use at meetings, work, or home prior to selecting what device to purchase. The center does not sell devices, but provides information on local resources and catalogs for devices and has application forms available for anyone needing assistance to purchase the assistive device. The applications have a list of the equipment that is available on the subsidy program. Not all types of devices or models are available. If you need help buying an assistive device, please contact one of the following demonstration and loan centers for an appointment.

BOISE

UNITED CEREBRAL PALSY OF
IDAHO, INC. –
5420 Franklin Road, Suite A
Boise, ID 83705
(208) 377-8070
(208) 322-7133 (Fax)

MOSCOW

Disability Action Center (DAC)
124 East Third Street
Moscow, ID 83843
(208) 883-0523 (Voice/TTY)
(208) 883-0524 (Fax)

POCATELLO

IDAHO STATE UNIVERSITY
Department of Speech Pathology and
Audiology
650 Memorial, Building 68
Pocatello, ID 83209
(208) 282-3495

TWIN FALLS

Living Independence Network Corp.
132 Main Street South
Twin Falls, ID 83301
(208) 733-1712

IDAHO FALLS

Living Independently for Everyone
(LIFE)
2110 Rollendet Avenue
Idaho Falls, ID 83402
(208) 529-8610 (Voice/TTY)
(208) 529-6804 (Fax)

For Subsidy Grant Applications Only

COEUR D'ALENE SATELLITE OFFICE

Disability Action Center (DAC)
Northwest
1323 Sherman, Suite 5
Coeur d'Alene, ID 83814
(208) 664-9896 (Voice/TTY)
(800) 854-9500

For the more information, contact the Council for the Deaf and Hard of Hearing at:
(208-334-0879 or 800-433-1323 Voice, or 208-334-0803 TTY, or 800-433-1361 TTY)



IDAHO HANDS & VOICES

IDAHO
HANDS&
VOICES

*What Works for your Child
is What Makes the Choice Right*

Idaho Families for Hands & Voices is a Statewide parent driven, parent to parent support organization dedicated to providing compassionate, non-biased support for families who have infants and young children with a hearing loss. Hands & Voices is comprised of families with deaf or hard of hearing children using a variety of modes of communication. Idaho Families for Hands & Voices is closely associated with the Hands & Voices National organization www.handsandvoices.org

Our Idaho program is managed by a statewide parent/professional advisory group and is facilitated by regional parent consultants.

Shortly after diagnosis with parent permission, Hands & Voices regional parent consultants contact parents of newly diagnosed children with hearing loss. Parent consultants deliver “Help and Hope” and counsel with families. Additional activities and interest groups may be available within Idaho’s 7 regions.

Please contact the State Council for the Deaf and Hard of Hearing office for more information, or link to Hands & Voices through the Council’s website.



Non-biased support for families of children who are deaf or hard of hearing



For State Chapter Information:

Council for the Deaf and Hard of Hearing
1720 Westgate Dr.
Boise, ID 83704
(208) 334-0879
(208) 334-0803 TTY
(800) 433-1323
(800)433-1361 TTY
www2.state.id.us/cdhh

For National Information:

Families for Hands & Voices National
PO Box 371926
Denver, CO 80237
(303) 300-9763
(866) 433-0422
www.handsandvoices.org

IDAHO INFANT TODDLER PROGRAM:

Early Intervention Services (Part C) / Child Development Centers

Region	Early Intervention Specialist
Region 1	Sue Nelson Child Development Center 2195 Ironwood Court Coeur d'Alene, ID 83814 208-769-1409 nelsons@idhw.state.id.us
Region 2	C.R. "Pete" Petersen Child Development Center 2604 16th, PO Drawer B Lewiston, ID 83501 208-799-3460 petersep@idhw.state.id.us
Region 3	Joyce Scott Child Development Center 3402 Franklin Caldwell, ID 83605 208-465-8460 ext. 316 scottj@idhw.state.id.us
Region 4	Anna Smith Child Development Center 1720 Westgate Dr., Suite B Boise, ID 83704 208-334-0920 smitha@idhw.state.id.us
Region 5	Annette Wilkinson Child Development Center 803 Harrison St. Twin Falls, ID 83301 208-736-2182 wilkinsa@idhw.state.id.us
Region 6	Sharon Rivas Child Development Center 421 Memorial Drive Pocatello, ID 83201 208-234-7900 rivass@idhw.state.id.us
Region 7	Karen Nuckols, Acting Child Development Center 2475 Leslie Ave. Idaho Falls, ID 83403 208-525-7223 nuckolsk@idhw.state.id.us

The Idaho Infant Toddler Program is like an umbrella over different agencies. Services and funds are used to ensure that all existing programs are working together effectively and to fill in gaps where needed services don't exist.

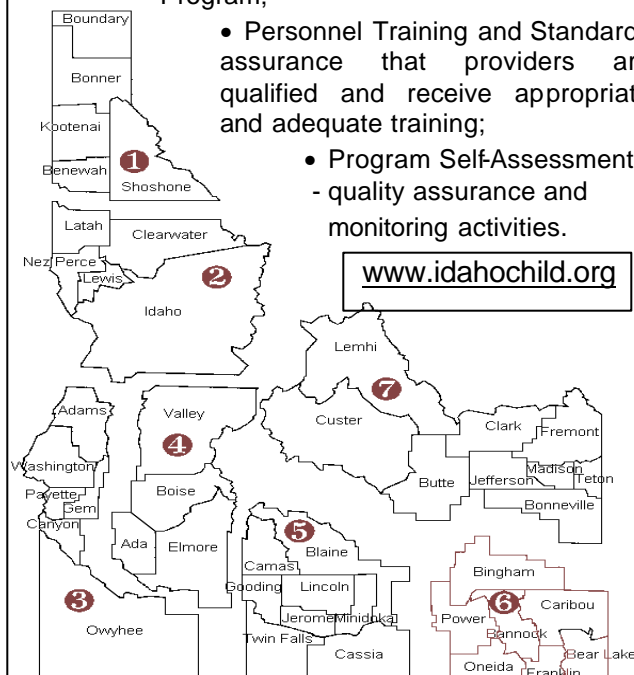
Early Intervention Program components include:

- Public Awareness and Community Education Campaigns;
- Child Find - identification of children who would benefit from services;
- Evaluation and Assessment - activities to determine a child's current developmental status;
- Individualized Family Service Planning – a plan that addresses the child's and family's unique needs;
- Early Intervention Services - therapeutic and support services provided in a "natural setting" such as the home or a child-care center;
- Service Coordination - activities which ensure needed services are available, accessible, and cost-effective;
- Procedural Safeguards - parent's rights which guarantee timeliness and confidentiality;
- Transition Planning - procedures to help families access appropriate services when a child leaves the Infant Toddler Program;

- Personnel Training and Standards assurance that providers are qualified and receive appropriate and adequate training;

- Program Self-Assessment - quality assurance and monitoring activities.

www.idahochild.org



IDAHO SCHOOL

FOR THE DEAF AND THE BLIND- provides both residential services at its main campus in Gooding, Idaho, and outreach services through its seven regional offices.

1450 Main Street
 Gooding, ID 83330-1899
 (208) 934-4457
 (208) 934-8352
 info@isdb.state.id.us
www.isdb.state.id.us

Our vision is a safe, supportive environment for students, where educational opportunities are provided to gain knowledge, skills and values needed to perform to their potential in society.

PROVIDING EARLY INTERVENTION FOR FAMILIES OF INFANTS & TODDLERS WITH HEARING LOSS

Any child, birth to age three with a hearing loss, who resides in the state of Idaho is eligible for early intervention services from Idaho School for the Deaf and the Blind (ISDB). ISDB provides family centered early intervention through home visits. ISDB Outreach Consultants, or Parent/School Advisors (PSA's), across the state work with families to improve their communication techniques, maximize their child's auditory environment, and develop their child's potential language and cognition. Parents, siblings, extended family and PSA's discuss and practice strategies that work with young deaf or hard of hearing children. Together they develop an Individual Family Service Plan (IFSP) that respects the family's unique goals and abilities.

ISDB outreach services are free of charge for families with children with diagnosed hearing loss.

ISDB Regional Consultants will coordinate their services with the Idaho Infant/Toddler Program, Idaho Sound Beginnings, Idaho Hands & Voices and other parent groups, Lions Loaner Hearing Aid Bank, Idaho Deaf/Blind Project, Local School Districts, Local Physicians, Audiologists, Speech and Language Pathologists and Physical and Occupational Therapists.

If you have questions regarding your child's hearing, or Outreach, Residential or other Services provided by ISDB, please contact:

Mary Dunne, Director of Outreach, Deaf/Hard of Hearing mdunne@isdb.state.id.us

Or, you may contact a regional consultant at one of the offices listed below:

- | | |
|----------|---|
| Region 1 | 2195 Ironwood Court, Coeur d'Alene, ID 83814
208-769-1431 Voice/TDD |
| Region 2 | C/O Lewis-Clark State College
8 th Ave. & 6 th St., Lewiston, ID 83501
208-743-2075 Voice/TDD |
| Region 3 | 823 Sprecht Ave., Suite D, Caldwell, ID 83605
208-454-7767 Voice/TDD |
| Region 4 | The Meridian Building
1406 N. Main Street, Meridian, ID 83642
208-888-3289 Voice/TDD |
| Region 5 | Idaho School for the Deaf & the Blind
1450 Main St., Gooding, ID 83330-1899
208-934-4457 Voice/TDD |
| Region 6 | Main Street Plaza
427 N Main, Suite J, Pocatello, ID 83204
208-236-6057 Voice/TDD |
| Region 7 | 3250 Rollandet, Idaho Falls, ID 83407
208-525-7298 |



IDAHO SOUND BEGINNINGS

NEWBORN HEARING SCREENING IN IDAHO HOSPITALS

On April 1, 2000, the Idaho Council for the Deaf and Hard of Hearing was awarded a four-year grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services, to implement an Early Hearing Detection and Intervention Program (EHDI) for the state of Idaho.

The EHDI grant has allowed the Council for the Deaf and Hard of Hearing to promote Early Hearing Detection and Intervention throughout the State, and formalize screening, referral, and intervention services for babies born with hearing loss.

The Idaho Sound Beginnings Advisory Committee includes:

Sherry Iverson, RN, Director of Women's and Children's Community Education, St. Luke's
Regional Medical Center

Mary Jones, BUS, Manager of the Idaho Infant Toddler Program

Carolee Eslinger, MPH, LSW, Program Specialist, Idaho Infant Toddler Program

Toni Lockhart, Director of Quality and Health Resources, Idaho Hospital Association

Evelyn St. Clair, MD, Pediatrician

Jill Jirek, BA, The deaf mother of a hard of hearing child

Kathleen Wachtler, Au.D., CCC-A, Pediatric Audiologist, Idaho Elks Rehabilitation Hospital

Pennie Cooper, Executive Director, Idaho Council for the Deaf and Hard of Hearing

Ron Schow, Ph.D, Professor, Idaho State University, Department of Speech and Hearing

Christina Giso, BA, MBA, Genetic Services Manager and Idaho Newborn Screening
Coordinator

Lesa Coleman, MS, Parent of children with hearing loss

Susie Jones, Parent of a child with a cochlear implant

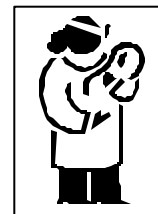
Bob Seeheusen, CEO, Idaho Medical Association

Mary Dunne, MS, Director of Outreach, Idaho School for the Deaf and the Blind

Bee Biggs-Jarrell, RN, BSN, MPA, Project Coordinator, Idaho Sound Beginnings

Jill Beck, MD, Pediatric Otolaryngologist, Southwest Idaho ENT

Brett Harrell, BS, MAT, Manager, Children's Special Health Program



UNITED CEREBRAL PALSY OF IDAHO, INC

Understanding Disabilities
Creating Opportunities

MISSION - UCP supports all people with disabilities to discover, obtain and use assistive technology and other resources to advance learning, independence, work opportunities, and full inclusion in their communities.

SERVICES

- Assistive Technology Loaning Library - over 2,400 items available
- Computer Lab- Beginning and advanced - computer software and hardware aids
- Information and referrals
- Consultations
- Training, demonstrations and public education
- Product information, technology publications, and vendor information available



ASSISTIVE TECHNOLOGY AND TOY LOANING LIBRARY

- **Communication/Telecommunication devices – TTY's, amplified phones, visual alerting devices for phones, doorbells, and alarm clocks.**
- Adapted and developmental toys for children
- Adapted switches for toys, computers and communication devices
- Self-help tools for independent living
- Computer hardware and software -
 - Alternative keyboards
 - Mouse alternatives
 - Early childhood software
 - Voice-activated software
- Books
- Writing aids



COMPUTER LAB AND DEMONSTRATION CENTER

- Try out adaptive computer hardware, like Intellikeys or the Tracker hands-free mouse
- Use specialized software to learn, improve skills or even to talk to the computer
- Work independently or with your own helper
- Come see the latest developments from AT vendors



Kathy Griffin
UCP Program Director
5420 W Franklin Road, Suite A
Boise, ID 83705

Phone & TTY (208)377-8070
Fax (208)322-7133
Toll Free 888-289-3259

Hours:
Monday - Friday
10:00 a.m. - 4:30 p.m.

NATIONAL RESOURCES

The following resources may be helpful in providing important information and support as you work with your child and the other members of his or her care team.

Alexander Graham Bell Association for the Deaf and Hard of Hearing

3417 Volta Place NW, Washington, DC 20007
(202) 337-5220 (voice and TTY)
Toll-free: 1-800-HEAR-KID (1-800-432-7543)
www.agbell.org

American Academy of Audiology

8201 Greensboro Drive, Suite 300, McLean, VA 22102
(800) 222-2336
(703) 610-9022 (TTY)
e-mail: cfisk@audiology.org
www.audiology.org

American Academy of Otolaryngology Head and Neck Surgery

One Prince Street, Alexandria, VA 22314
(703) 836-4444
(703) 519-1585 (TTY)
www.entnet.org

American Society for Deaf Children

PO Box 3355
Gettysburg, PA 17325
(717) 334-7922 (voice/TTY)
www.deafchildren.org

American Speech-Language-Hearing Association (ASHA)

10801 Rockville Pike, Rockville, MD 20852
(800) 638-8255 (voice and TTY)
www.asha.org

Auditory-Verbal International, Inc. (AVI)

2121 Eisenhower Ave., Suite 402, Alexandria, VA 22314
(703) 739-1049 (Voice), (703) 739-0874 (TDD)
www.auditory-verbal.org

Beginnings for Parents of Children Who are Deaf or Hard of Hearing, Inc. (Beginnings)

P.O. Box 17646, Raleigh, NC 27619
(919) 571-4843 (Voice & TTY)
www.ncbegin.org

Better Hearing Institute

PO Box 1840, Washington, DC 20013
1-800 EAR-WELL (Voice & TDD)

Boys Town National Research Hospital

555 N. 30th Street , Omaha, NE 68131
(402) 498-6511 (voice)
(402) 498-6543 (TTY)
1-800-282-6657
www.boystown.org/btnrh
www.babyhearing.org

Caption Media Program (CMP), National Association of the Deaf

1447 East Main St
Spartanburg, SC 29307
1-800-237-6213
1-800-237-6819 TTY
www.cfv.org

Central Institute for the Deaf (CID)

4560 Clayton Ave, St. Louis, MO 63110
(314) 977-0000, (314) 977-0001 TTY
(877) 444-4574
bfisher@cid.wustl.edu
www.cid.wustl.edu

Cochlear Implant Association, Inc. (CIAI)

5335 Wisconsin Ave. NW, suite 440
Washington, DC 20015-2052
(202) 895-2781
info@cici.org
www.cici.org

Council for Exceptional Children

1110 North Glebe Rd, Suite 300, Arlington, VA 22201

(703) 620-3660

(866) 915-5000 TTY

1-888-CEC-SPED

www.cec.sped.org

Cued Language Network of America

P.O. Box 1142, Draper, UT 84020

(888) 523-0964 V/TTY

www.cuedlanguage.org

Deafness Research Foundation (DRF) and the National Campaign for Hearing Health (NCHH)

1050 17th St., NW, Suite 701, Washington, DC 20036

(202) 289-5850 (Voice & TTY)

www.drf.org

www.hearinghealth.net

Families for Hands & Voices, National

PO Box 371926, Denver, CO 80237

(303) 300-9763

1-866-422-0422

www.handsandvoices.org

Gallaudet University

800 Florida Ave., NE

Washington, DC 2002

(202) 651-5000 (Voice & TTY)

www.gallaudet.edu

www.clerccenter.gallaudet.edu

Hear Now

6700 Washington Ave. S.

Eden Prairie, MN 55344

1-800-648-4327

nonprofit@starkey.com

www.sotheworldmayhear.org

Holley Ear Institute

22151 Moross Rd. Bldg. 1, Suite 223
Detroit, MI 48236-2172
(313) 343-7583
(313) 343-8789 TTY

House Ear Institute (HEI)

2100 West Third Street , Los Angeles, CA 90057
(213) 483-4431
(213) 484-2642
www.hei.org

Infant Hearing Resources

Hearing & Speech Institute
3515 SW Veterans Hospital Road, Portland, OR 97201
(503) 228-6479

International Hearing Dog, Inc.

5909 East 89th Ave., Henderson, CO
(303) 287-3277 (Voice &TDD)
www.ihdi.org

John Tracy Clinic

806 West Adams Blvd. , Los Angeles, CA 90007-2599
(213) 748-5481 (voice)
(213) 749-8651 (TTY)
1-800-522-4582
www.jtc.org

League for the Hard of Hearing

71 West 23rd Street , New York, NY 10010-4162
(917) 305-7700
(917) 305-7999
www.lhh.org

Marion Downs National Center for Infant Hearing

University of Colorado at Boulder,
Dept. of Speech, Language & Hearing
Campus Box 409, Boulder, CO 80309-0409
(303) 492-6283, (303) 492-4124
www.colorado.edu/slhs/mdnc

National Association of the Deaf

814 Thayer Avenue, Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 TTY
www.nad.org

National Cued Speech Association (NCSA)

23970 Hermitage Road, Cleveland, OH 44122
1-800-459-3529
www.cuedspeech.org

National Center for Hearing Assessment and Management –

Utah State University
Information & links to many useful sites
www.infanthearing.org

National Deaf Education Network and Clearinghouse Info to

Go – Gallaudet University
800 Florida Ave. NE, Washington, DC 20002-3695
www.clerccenter.gallaudet.edu

National Information Center on Deafness

Gallaudet University
800 Florida Ave. NE, Washington, DC 20002-3695
(202) 651-5060
(202) 651-5052 (TTY)
www.gallaudet.edu

National Institute on Deafness and Other Communication Disorders (NIDCD)

1 Communication Avenue, Bethesda, MD 20892-3456
(301) 496-7243
1-800-241-1044
(301) 241-1055 TTY
1-800-241-1055 TTY
www.nidcd.nih.gov

The Oberkottter Foundation

PO Box 50215, Palo Alto, CA 94303-9465
Free Parents' Information Kit
(877) 672-5332 (voice)
(877) 672-5889 (TTY and FAX)
www.oraldeaf.org

Options

7056 S. Washington Ave., Whittier, CA 90602
(310) 945-8391

Registry of Interpreter for the Deaf

8630 Fenton St., Suite 324, Silver Spring, MD 20910
(301) 608-0050 (Voice/TDD)
www.rid.org

Self-Help for Hard of Hearing People, Inc.

7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TTY)
www.hearingloss.org

Signing Exact English Center for Advancement of Deaf
Children (S.E.E. Center)

PO Box 1181, Los Alamitos, CA 90720
(562) 430-1467
www.seecenter.org

SKI-HI Institute – Utah State University

6500 Old Main Hill
Logan, UT 84322-6500
(435) 797-5600
www.skihi.org

TDI (formerly Telecommunications for the Deaf, Inc.)

8630 Fenton Street, Suite 604
Silver Spring, MD 20910-3803
(301) 589-3786
(301) 589-3006 TTY
www.tdi-online.org

World Federation of the Deaf

PO Box 65, 00411 Helsinki, Finland

358-9-580-3573 TTY

www.wfdnews.org

FINANCIAL RESOURCES:

Having a deaf or hard of hearing child can sometimes cause periods of financial stress. Financial help is available through many agencies/organizations.

The following provide help to parents of deaf or hard of hearing children who qualify for services.

Alexander Graham Bell Association for the Deaf, Inc.

Provides services to people who are deaf or hard of hearing. Gives stipends for financial aid for infant children through 21 years of age. Call for information. Requests must be in writing.

3417 Volta Place, N.W.
Washington, D.C. 20007
(202) 337-5220 (V/TTY)
1-800 432-7543
www.agbell.org

Assistance League of Boise

Assistance with obtaining hearing aids and assistive devices.
5825 Glenwood St.
Boise, Idaho 83714-0104
(208) 377-4327
www.alboise.org

Hearing Impaired Kids Endowment Fund (HIKE)

Provides assistance to parents of deaf or hard of hearing children for equipment.
The HIKE Fund
233 West 6th St.
Papillion, NE 68046
(402) 592-7987
www.iojd.org

Kathryn Kinney
Boise
(208) 323-0789



Hear Now

A nonprofit organization serving hard of hearing clients throughout the U.S. providing hearing health care assistance to qualified applicants (hearing aids and cochlear implants).
6700 Washington Ave. South
Eden Prairie, MN 55344
(800) 648-4327
www.sotheworldmayhear.org
nonprofit@starkey.com

IRS for Deaf

Check for tax deductions and tax credits.
(800) 829-4059
www.irs.gov

Social Security Administration Office

Check your local telephone book under Federal Government, Social Security Administration for telephone numbers in your area.

Lions Sight and Hearing Conservation Foundation, Inc.

Gene Strate, Trustee
Southern Idaho and Oregon
(208) 855-9366

Veteran's Administration

Programs for children of veterans who are permanently disabled.
Boise, Idaho
(800) 827-1000

Idaho Assistive Device Subsidy Program

A subsidy program administered by United Cerebral Palsy of Idaho, Inc. through a grant from the Council for the Deaf and Hard of Hearing. Helping people who are deaf or hard of hearing to purchase assistive devices.

Applications and information are available at **Assistive Device Demonstration and Loan Centers**
A complete listing of regional centers can be found in the State Resources section.

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Idaho Vocational Rehabilitation

Region I

1010 Ironwood Dr., Suite 101
Coeur d'Alene, ID 83814-2699
(208) 769-1441 (V/TTY)
(208) 769-1440 (FAX)
Bob Carter
Deaf and Hard of Hearing
Consultant

Region II

1118 F St.,
P O Box 1368
Lewiston, ID 83501
(208) 799-5070 (V)
(208) 799-55072 (TTY)
Suzanne Anderson-Ruble
Deaf and Hard of Hearing
Consultant

Region III (Boise East)

3350 Americana Terrace, Suite 210
Boise, ID 83706

(208) 334-3650 (V)
(208) 334-3661 (FAX)

Region IV

245 3rd Avenue N
Twin Falls, ID 83301-6131
(208) 736-2156 (V/TTY)
(208) 736-2168 (FAX)
Mendie Moyes
Deaf and Hard of Hearing Consultant

Region V

1070 Hiline, Suite 200
Pocatello, ID 83201-2947
(208) 236-6333 (V/TTY)
(208) 236-6304 (FAX)
Wes Van Voohen
Deaf and Hard of Hearing Consultant

Region VI

1825 Hoopes Ave.
Idaho Falls, ID 83404-8018
(208) 525-7149 (V/TTY)
(208) 525-7104 (FAX)
Matt Queen
Deaf and Hard of Hearing Consultant

Region VII

3110 E. Cleveland #A7
Caldwell, ID 83605
(208) 454-7606 (V/TTY)
(208) 454-7630 (FAX)
Janet Job
Deaf and Hard of Hearing Consultant

Region VIII (Boise West)

10200 W. Emerald #101
Boise, ID 83704
(208) 327-7411 (V/TTY)
(208) 327-7417 (FAX)
Michelle Clarke
Deaf and Hard of Hearing Consultant

GENETICS OF HEARING LOSS RESOURCES

BOISE, ID

Anne Spencer, MS

Certified Genetic Counselor

State of Idaho Genetic Services Program

2220 Old Penitentiary Rd.

Boise, ID 83712

Phone (208) 334-2235 ext. 258

spencera@idhw.state.id.us

WEBSITES:

Genetics and Deafness: Basic Concepts, Genetic Syndromes,
Boys and Girls Town National Research Hospital, Omaha, NE

www.babyhearing.org

www.boystownhospital.org/parents/info/genetics.asp

Hereditary Hearing Loss and Deafness Overview, GeneClinics

www.geneclinics.org/profiles/deafness-overview/details.html

Gallaudet University, Department of Biology

800 Florida Avenue, NE

Washington, DC 20002

Phone: 202-651-5258 (V/TTY)

Toll free: 800-451-8834, ext. 5258

<http://depts.gallaudet.edu/genetics/>



**PEDIATRIC GENETIC
SERVICES PROGRAMS:**



BOISE, ID

Genetic Services Program
Department of Health and Welfare, Boise,
ID

Genetics Board Certification:
Genetic Counseling, General Genetics
(208) 334-2235 ext. 261
Fax: (208) 334-2382

HELENA, MT

Shodair Hospital
Montana Medical Genetics Program,
Helena, MT
Genetics Board Certification: Medical
Genetics
(406) 444-7500
Fax: (406) 444-1022
E-mail: mtgene@shodair.org
Satellite Clinics: Billings; Bozeman;
Butte; Great Falls; Kalispell;
Miles City; Missoula; Sidney

PORTLAND, OR

Oregon Health Sciences University
Genetics/Birth Defects Clinic,
Portland, OR
Genetics Board Certification:
Genetic Counseling, Medical Genetics
(503) 494-8307
Fax: (503) 494-2786
E-mail: genetics@ohsu.edu

SALT LAKE CITY, UT

University of Utah Medical Center
Medical Genetics Clinic,

Salt Lake City, UT

Genetics Board Certification:
Genetic Counseling, Medical Genetics
(801) 581-8943
Fax: (801) 585-7252
Satellite Clinics: Blanding; Cedar City;
Moab; Price; Richfield; St. George;
Vernal

SEATTLE, WA

Children's Hospital and Regional Medical
Center
Medical Genetics Clinic,
Seattle, WA
Genetics Board Certification:
Genetic Counseling, Medical Genetics
(206) 528-2665
Fax: (206) 517-2495
Office Telephone: (206) 526-2056
Satellite Clinics: Bellingham

University of Washington Medical Center
Medical Genetics Clinic,
Seattle, WA
Genetics Board Certification:
Genetic Counseling, Medical Genetics
(206) 616-2135
Fax: (206) 616-2414
E-mail: geninfo@u.washington.edu

SPOKANE, WA

Inland Northwest Genetics Clinic,
Spokane, WA
Genetics Board Certification:
Genetic Counseling, Medical Genetics
(509) 473-7115
Fax: (509) 473-7904

LEGAL RESOURCES:

There are specific laws which protect our rights and those rights of your deaf or hard of hearing child. The following agencies are available to answer your questions about legal matters.

Idaho Legal Aid Services, Inc

Boise:

P O Box 1683
Boise, ID 83701
(208) 345-0106

Caldwell:

P O Box 1116
Caldwell, ID 83606
(208) 454-2591

Coeur d'Alene:

P O Box 1439
CDA, ID 83814
(208) 667-9559

Idaho Falls:

482 Constitution Way
Idaho Falls, ID 83402
(208) 524-3660

Lewiston:

P O Box 973
Lewiston, ID 83501
(208) 743-1556

Pocatello:

P O Box 1785
Pocatello, ID 83204
(208) 233-0079

Twin Falls:

P O Box 1296
Twin Falls, ID 83303
(208) 734-7024



Idaho State Council for the Deaf and Hard of Hearing

A state agency serving persons who are deaf or hard of hearing to improve the quality of life for Idahoans who are deaf or hard of hearing by providing information, serving as an advocate and increasing services and access to them.

1720 Westgate Drive, Suite A
Boise, Idaho 83704
(208) 334-0879 (V)
(800) 433-1323 (V)
(208) 334-0803 (TTY)
(800) 433-1361 (TTY)
www2.state.id.us/cdhh/

To file a complaint with the U.S. Department of Justice for non-compliance with the Americans With Disabilities Act, call the Idaho State Council for the Deaf and Hard of Hearing for information.

**Comprehensive Advocacy, Inc.
(CO-AD)**

Acts as advocates for the rights of the disabled.

Boise:

Co-Ad, Inc.
4477 Emerald, Suite B-100

Comprehensive Advocacy, Inc.

Boise, ID 83706
(208) 336-5353 (V/TDD)
(800) 632-5125

Moscow:

Co-Ad, Inc.
107 East 4th Street
Moscow, ID 83843
(208) 882-0962 (V/TDD)

Pocatello:

Co-Ad, Inc.
845 C West Center, Suite 108
Pocatello, ID 83204
(208) 232-0922 (VTDD)

Idaho Parents Unlimited, Inc. (IPUL)

600 N. Curtis #100
Boise, Idaho 83706
(208) 342-5884
(800) 242-4785

National Association of the Deaf

Legislative advocate for equal access to
communication and employment
814 Thayer Avenue
Silver Springs, MD 20910-4500
(301) 587-1788 (V)
(301) 587-1789 (TTY)
(301) 587-1791 (FAX)
<http://www.nad.org>

CaDARA

Develops, promotes and expands
services, research, and legislation to
individuals who are deaf and hard of
hearing.

625 Cherry Street
Santa Rosa, CA 95404
(707) 526-8341

Idaho Volunteer Lawyers Program

525 W. Jefferson
Boise, Idaho 83702
(208) 334-4510
<http://www.state.id.is/isb>

**The Idaho Task Force on the Americans With
Disabilities Act**

Will provide information but is not
responsible for enforcement.

1311 W. Jefferson
Boise, Idaho 83702
(208) 334-5590 (V/TTY)
(208) 334-5563 (FAX)
Email: IDTaskFrc@aol.com

**The Council of Parent Attorneys and
Advocates**

An independent, nonprofit, tax-exempt
organization of attorneys, advocates and
parents established to improve the quality
and quantity of legal assistance for parents
of children with disabilities.

1321 Pennsylvania Ave, SE
Washington, DC 20003-3027
(202) 544-2210
www.copaa.net

Other Websites:

www.ideapractices.org
www.wrightslaw.com



INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA) PART C

The early intervention program for infants and toddlers with disabilities- provides financial assistance to States to:

- Maintain and implement a statewide, comprehensive coordinated interagency system of early intervention services for infants and toddlers with disabilities and their families;
- Enhance the States' capacity to provide quality early intervention services;
- Identify and evaluate at-risk infants and toddlers.

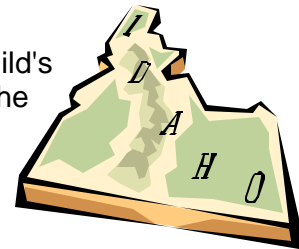
Early Intervention services must be:

- Designed to meet the developmental needs of each eligible child and the needs of the family related to enhancing the child's development;
- Selected in consultation with the parents;
- Provided by qualified personnel;
- Conform with an Individual Family Service Plan (IFSP);
- Provided at no cost (unless the law provides for a payment system by the family);
- Meet any State standards.

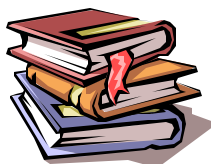
For additional information on IDEA consult the web-sites listed under "Information on IFSP and IEP Special Education Advocacy".

IDAHO LAW ALSO DEFINES SPECIFIC REQUIREMENTS FOR EARLY INTERVENTION WHICH INCLUDE:

- To reaffirm the importance of the family in all areas of the child's development and to reinforce the role of the family in the decision making processes regarding their child;
- To provide assistance and support to the family of an infant or toddler with a disability that addresses the individual needs of the family;
- To develop and implement with available resources a statewide screening and tracking system for infants and toddlers at risk;
- To develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for all infants and toddlers with disabilities and their families;
- To enhance the capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities;
- To facilitate the coordination of payment for early intervention services from federal, state, local, and private sources including public and private insurance coverage; and
- To guarantee financial assistance for the purposes of coordinating early intervention services in communities and to enhance their capacity to provide individualized services to infants and toddlers with disabilities and their families.



PUBLICATIONS:



The following are newsletters, newspapers, and periodicals that you can order for your reading enjoyment. They will keep you current on the latest information available to you as the parent of a child who is deaf or hard of hearing.

Opportunity

Newsletter of the Idaho State Council for the Deaf and Hard of Hearing
(208) 334-0879 (V)
(800) 433-1323 (V)
(208) 334-0803 (TTY)
(800) 433-1361 (TTY)

**Idaho Parents Unlimited, Inc.
Newsletter**

(208) 342-5884
(800) 242-4785

Information from HEATH

The national clearinghouse on postsecondary education for individuals with disabilities, a program of the American Council on Education (ACE)

Heath Resource Center

1 Dupont Circle, Suite 800
Washington, D.C. 20036
(202) 939-9320 (V/TTY)
(800) 544-3284 (V)

(202) 833-4760

Deaf, Counseling, Advocacy, and Referral Agency (DCARA)

Monthly circulation
125 Parrott St.
San Leandro, CA 94577
(510) 483-6914 (TTY)

John Tracy Clinic Bulletin

Three times per year
806 W. Adams Boulevard
Los Angeles, CA 90007
(213) 748-5481 (V)
(213) 747-2924 (TTY)
(800) 522-4582 (V/TTY)
(213) 749-1651 (FAX)

NICHCY News Digest

National Information Center for Children and Youth with Disabilities
P O Box 1492
Washington, D.C 20013-1492
(202) 884-8200 (V/TTY)
(800) 695-0285 (V/TTY)
(202) 884-8441 (FAX)

Hearing Loss: The Journal of Self Help for Hard of Hearing People

Self Help for Hard of Hearing People, Inc.
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814
(301) 657-2248 (V)
(301) 657-2249 (TTY)
(301) 913-9413 (FAX)
Subscription comes with membership

The Volta Review (Journal)

Volta Voices (Magazine)

Alexander Graham Bell Association for the Deaf, Inc.

3417 Volta Place, N.W.
Washington, D.C. 20007
(202) 337-5220 (V/TTY)

(202) 337-8314 (FAX)

The Endeavor

American Society for Deaf Children
1820 Tribute Road, Suite A
Sacramento, CA 95815
(800) 942-2732 (Parent Hotline)

Better Hearing Institute

Distribute publications on hearing loss
515 King St. #420
Alexandria, VA 22314
(800) 327-9355

SEE What's Happening

Quarterly newsletter of The S.E.E.
Center for the Advancement of Deaf
Children
P O Box 1181
Los Alamitos, CA 90720
(562) 430-1467 (V/TTY)
(562) 795-6614 (FAX)

Catalogs of videotaped, computer-
assisted, and printed resources for
parents and children are also
available.

Harris Communications, Inc.

15159 Technology Drive
Eden Prairie, MN 55344-2277
(800) 825-6758 (V)
(800) 211-4360 (VCO)
(800) 825-9187 (TTY)
www.harriscomm.com

Most comprehensive one-stop
shopping catalog of products and
informational resources for deaf and
hard of hearing persons and their
families from birth to adulthood.
Company founder, who is the father of
a deaf child, was frustrated by the lack
of resources in one easily accessible
place. The catalog is free.

Gallaudet University Press

800 Florida Avenue, N.E.
Washington, D.C. 20002-3695
(800) 621-2736 (V)
(800) 621-8476 (FAX)
Internet: PUBNET@202-5280

A non-profit division of the only liberal
arts university in the world for deaf and
hard of hearing students. Gallaudet
University has been a leader in early
intervention and pre school education
programs. Catalog contains published
works based upon model programs used
at Kendall Demonstration Elementary
School (KDES) as well as books of general
interest.

Titles include such offerings as:

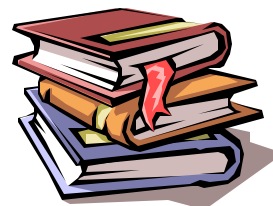
Kid-friendly Parenting with Deaf and
Hard of Hearing Children

Deaf Like Me

The Silent Garden: Raising Your Deaf
Child

You and Your Deaf Child: A Self-help
Guide for Parents of Deaf and Hard of
Hearing Children

Choices in Deafness: A Parent's Guide to
Communication Options



Meridian Library District

Sponsored by The Assistance League
of Boise and the Higgs Family
Foundation
1326 West Cherry Lane
Meridian, ID 83642
(208) 888-4451

The Linda Bove American Sign

Language Video Collection contains
over 200 videos, for adults and
children, discussing American Sign
Language, deafness and deaf culture.

Video Categories include:

- Basic American Sign Language (ASL) Lessons,
- Intermediate to Advanced American Sign Language Lessons,
- American Sign Language Lessons with a Focus on Infants and Toddlers,
- Issues of Interest to Parents with Young Children,
- American Sign Language Lessons, Songs, Programs & Stories for Children (includes fairy tales, Christmas stories, the Land Before Time series, A Book a Day Series and more).
- Sign Language Interpreting,
- Classic Literature translated into American Sign Language,
- Poetry and Artistic American Sign Language,
- Stories, Comedy, and Drama,
- History of Deaf People and Sign Language,

- Biographies,
- Religion and Inspiration,
- How to...
- Health and Safety,
- Reference Materials, and
- CD-ROMs

Obtaining Videos:

Videos are
accessible
all libraries in
consortium-



through
the

Ada Community, Boise Public, Caldwell
Public, Eagle Public, Garden City,
Meridian District and Nampa Public
Libraries.

If an individual lives outside of these
areas they may be able to access the
videos through an interlibrary loan (ILL)

**ADDITIONAL RESOURCES YOU
MAY FIND HELPFUL**

Dogs for the Deaf, Inc.

10175 Wheeler Road
Central Point, OR 97502-9360
(541) 826-9220 (V)
www.dogsforthe deaf.org
Mission is to rescue dogs from
shelters, train them to serve as the
ears of people who are deaf or hard
of hearing. The dogs are then
placed with qualified applicants.

**Canine Companions for
Independence**

2965 Dutton Ave., PO Box 445
Santa Rosa, Ca 95402
(707) 577-1700
(707) 577-1756 (TTY/TDD)
www.caninecompanions.org

Handworks, Inc.

1562 1st Ave., Suite 134
New York, NY 10028
Clothing accessories created and
designed using American Sign
Language (ASL)

Catalogs for special communication
needs:

Carolyn's

(800) 648-2266

National Association of the Deaf

(301) 587-1788

Weitbrecht Communications

2716 Ocean Park Blvd #1007
Santa Monica, CA 90405
(800) 233-9130 (V/TTY)
(310) 452-8613 (V)
(310) 452-5460 (TTY)
(310) 450-9918 (FAX)
Internet: <http://www.weitbrecht.com>
Email: sales@weitbrecht.com

**Alexander Graham Bell Association
of the Deaf**

(202) 337-5220

Gallaudet Bookstore

(202) 651-5342

"ILY" Cookie Cutter

Red plastic cookie cutter in "I-Love-
You" sign hand shape.
(562) 430-1467 (S.E.E. Center)

All in Favor: Sign Chocolate

A 77 page cookbook of chocolate
recipes illustrated with signing
bears.
(562) 430-1467 (S.E.E. Center)

A SAMPLING OF WEB-SITES BY TOPIC to help you get started in your search for Information, Support, and Understanding.

(Please see the State and National Resource listings for more information on many of these organizations.)

INFORMATION ON UNDERSTANDING YOUR CHILD’S HEARING LOSS:

www.asdc.org	American Society for Deaf Children Fact Sheets
www.babyhearing.org	Boys Town Hospital site for Infant Hearing
www.handsandvoices.org	Families for Hands & Voices
www.nichcy.org	National Information Center for Children and Youth with Disabilities
www.agbell.org	Alexander Graham Bell Association for the Deaf and Hard of Hearing
http://www.nidcd.nih.gov	National Institute on Deafness and other Communication Disorders

INFORMATION ON FINDING SUPPORT FROM OTHER PARENTS:

www.handsandvoices.org	Families for Hands & Voices
www2.state.id.us/cdhh	Council for the Deaf and Hard of Hearing -with contact information for Idaho Families for Hands and Voices
www.gohear.org	Where Do We Go From Hear?
www.shhh.org	Self-Help for Hard of Hearing
www.parenttoparent.org	Parents Reaching Out to Parents-serving Bonner, Boundary, Kootenai, Shoshone and Benewah counties.
www.nichcy.org	National Information Center for Children and Youth with Disabilities
www.ncbegin.org	Beginnings for Parents of Children who are Deaf or Hard of Hearing, Inc.

INFORMATION ON EDUCATION AND EARLY INTERVENTION:

www.idahochild.org	Idaho Infant Toddler Program
www.sde.state.id.us/specialed	Idaho Bureau of Special Education
www.isdb.state.id.us	Idaho School for the Deaf and the Blind
http://www.dec-sped.org/	Division for Early Childhood, the Council for Exceptional Children
www.johntracyclinic.org	John Tracy Clinic

INFORMATION ON DEAF CULTURE AND COMMUNITY:

www.gallaudet.edu	Gallaudet University
http://clerccenter.gallaudet.edu	Laurent Clerc Center
www.nad.org	National Association of the Deaf
www.aslinfo.com	ASL (American Sign Language) Info.com
www.deaflibrary.org	The Deaf Resource Library

INFORMATION ON IFSP AND IEP SPECIAL EDUCATION ADVOCACY

www.ideapractices.org	IDEA Practices (Council for Exceptional Children)
www.wrightslaw.com	Wrights Law, Special Educ. Law and Advocacy Information
www.copaa.net	The Council of Parent Attorneys and Advocates
www.ed.gov/offices/OSERS/OSEP/	Office of Special Education Programs
www.nclb.gov/	No Child Left Behind, Department of Education
www.fape.org/	Families and Advocates partnership for Education (FAPE)
www.nectac.org	The National Early Childhood Technical Assistance Center

INFORMATION ON ASSISTIVE DEVICES:

www.harriscomm.com	Harris Communications
www.hitec.com/hitec.html	HITEC Group (batteries)
www.thebatteryclub.com	The Battery Club (batteries)
www.powerpalace.com	The Power Palace (batteries)
www.adcohearing.com	ADCO Hearing Products, Inc.
http://cart.ncraonline.org	Communication Access Realtime Translation (CART)
www.abledata.com	ABLEDATA
www.phonak.com	Phonak Hearing Systems
www.hamilton.net/relay	Hamilton Telecommunications/Idaho Relay Service
www.tedpa.org	Telecommunications Equipment Distribution Program Association
	AT&T Phone Stores
	Radio Shack

INFORMATION ON COCHLEAR IMPLANTS:

www.cici.org

Cochlear Implant Association, Inc.

www.listen-up.org

Forum and web-site developed by a parent

www.delphi.com/ParentsClarion

Advanced Bionics Corp. Parents of Clarion Children

www.cochlear.com

Coclear Corp.-Nucleus Forum

www.medel.com

MED-EL Corp.

Organization/Company	Website Address/URL
ABLEDATA	www.abledata.com
ADCO Hearing Products, Inc.	www.adcohearing.com
Advanced Bionics Corp. Parents of Clarion Children	www.delphi.com/ParentsClarion
Alexander Graham Bell Association for the Deaf	www.agbell.org
American Academy of Otorlarnngology Head and Neck Surgery	www.entnet.org
American Society for Deaf Children	www.deafchildren.org
American Society for Deaf Children Fact Sheet	www.asdc.org
American Speech-Language-Hearing Association	www.asha.org
Animated Sign Language Dictionary	www.bconnex.net~randys/index_nf.html
ASL	www.aslinfo.com
Assistance League of Boise	www.alboise.org
Auditory-Verbal International, Inc.	www.auditory-verbal.org
Beginnings	www.ncbegin.org
Boys Town Hospital Site for Infant Hearing	www.babyhearing.org
Boys Town Research Hospital	www.boystownhospital.org
Canine Companions for Independence	www.caninecompanions.org
Caption Media Program, National Association of the Deaf	www.cfv.org
CART -Communication Access Realtime Translation	http://cart.ncraonline.org
Central Institute for the Deaf	www.cid.wustl.edu
Cochlear Corporation	www.cochlear.com
Cochlear Implant Association, Inc.	www.cici.org
Council for Exceptional Children	www.cec.sped.org
Cued Language Network of America	www.cuedlanguage.org
Deaf Resource Library	www.deaflibrary.org
Deafness Research Foundation and the	www.drf.org
National Campaign for Hearing Health	www.hearinghealth.net
Division for Early Childhood, the Council for Exceptional Children	www.dec-sped.org/
Dogs for the Deaf, Inc.	www.dogsforthedeaf.org
Families and Advocates partnership for Education	www.fape.org
Families for Hands & Voices, National	www.handsandvoices.org
Forum and web-site developed by a parent	www.listen-up.org
Galludet University	www.gallaudet.edu
Hands & Voices	www.handsandvoices.org

Organization/Company	Website Address/URL
Harris Communications, Inc.	www.harriscomm.com
Hear Now	www.sotheworldmayhear.org
Hearing Depot	www.hearingdepot.com
HITEC Group (batteries)	www.hitec.com/hitec.html
House Ear Institute	www.hei.org
Idaho Assistive Technology Project	www.ets.uidaho.edu/idatech/
Idaho Bureau of Special Education	www.sde.state.id.us/specialed
Idaho Council for the Deaf and Hard of Hearing	www2.state.id.us/cdhh
Idaho Department of Education	www.sde.state.id.us/specialed
Idaho Infant Toddler Program	www.idahochild.org
Idaho Parents Unlimited, Inc.	www.ipuliadho.org
Idaho Project for Children and Youth with Deaf and Blindness	www.ets.uidaho.edu/cdhd
Idaho Registry of Interpreters for the Deaf	www.idahorid.org
Idaho School for the Deaf and Blind	www.isdb.state.id.us
Idaho Sound Beginnings	www2.state.id.us/cdhh
Idaho Speech, Language & Hearing	www.idahosha.org
Idaho Volunteer Lawyers Program	www.state.id.us/isb
IDEA practices	www.ideapractices.org
International Hearing Dogs, Ind.	www.ihdi.org
IRS for Deaf	www.irs.gov
ISHA-Idaho Speech, Language & Hearing Association	www.idahosha.org
John Tracy Clinic	www.jtc.org
Laurent Clerc Center	www.clerccenter.gallaudet.edu
League for the Hard of Hearing	www.lhh.org
Listen-Up	www.Listen-up.org
Marion Downs National Center for Infant Hearing	www.colorado.edu/slhs/mdnc
MED-EL Corp.	www.medel.com
My Babies Hearing	www.babyhearing.org
National Association for the Deaf	www.nad.org
National Cued Speech Association	www.cuedspeech.org
National Deaf Education Network and Clearinghouse	www.clerccenter.gallaudet.edu
Info to GO	
National Information Center for Children and Youth with Disabilities	www.nichcy.org
National Information Center of Deafness	www.gallaudet.edu

Organization/Company	Website Address/URL
National Institute on Deafness and Other Communication Disorders	www.nidcd.nih.gov
NCHAM-National Center for Hearing Assessment and Management	www.infanthearing.org
No Child Left Behind, Department of Education	www.nclb.gov
Office of Special Education Programs	www.ed.gov/offices/OSERS/OSEP/
Parents Reaching Out to Parents	www.parenttoparent.org
Phonak Hearing Systems	www.phonak.com
RID	www.rid.org/
Self-Help for Hard of Hearing People	www.shhh.org
Services for Deaf and Hard of Hearing in other states	http://clerccenter.gallaudet.edu/InfoToGo/501.html
Signing Exact English Center for Advancement of Deaf Children	www.seecenter.org
SKI-HI Institute – Utah State University	www.skihi.org
State Vocational Rehabilitation Agency	www.state.id.us/idvr/idvrhome.htm
TDI	www.tdi-online.org
TEDPA-Telecommunications Equipment Distribution Program Association	www.tedpa.org
The Battery Club (batteries)	www.thebatteryclub.com
The Council for Parents Attorneys and Advocates	www.copaa.net
The Hearing Center Online (Devices and Information)	www.hearingcenteronline.com
The National Early Childhood Technical Assistance Center	www.nectac.org
The Oberkotter Foundation	www.oraldeaf.org
The Power Palace (batteries)	www.powerpalace.com
Weitbrecht Communications	www.weitbrecht.com
Where Do We Go From Hear?	www.gohear.org
World Federation for the Deaf	www.wfdnews.org
Wrights Law, Special Educ. Law and Advocacy Information	www.wrightslaw.com

NOTES & CONTACT INFORMATION:

Screening and Intervention:	Child Development:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Audiologists:	Speech Pathologists:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Hearing Aid Dealers:	Assistive Device Dealers:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:

Support Groups:	Counselors:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Legal Resources:	Financial Resources:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Other Important Numbers:	
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:
Name:	Name:
Address:	Address:
Phone:	Phone:
Notes:	Notes:

REFERENCES:

ASL info.comwww.aslinfo.com

Information and resources related to American Sign Language (ASL), Interpreting and Deaf Culture

The American Academy of Pediatricswww.aap.org

141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098

Colorado Resource Guide for Families of Children who are Deaf/Hard of Hearing

Colorado Families for Hands & Voices and the Colorado Department of Education (2002)
PO Box 371926
Denver, CO 80237

Education Resources Information Center<http://www.eric.ed.gov>**For Families Guidebook**

Schuyler, V. & Sowers, J. (1998)
Hearing & Speech Institute
3515 SW Veterans Hospital Road
Portland, OR 97201-2997

John Tracy Clinic

www.jtc.org
806 West Adams Blvd.
Los Angeles, CA 90007-2599

My Baby's Hearing

www.babyhearing.org
Boys Town Research Hospital – Center for Hearing Loss in Children
555 N. 30th St.
Omaha, NE 68131-9909

National Center for Hearing Assessment and Management (NCHAM)**Utah State University**

www.infanthearing.org
2880 Old Main Hill
Logan, UT 84322-2880

Silence

Mary Reis (1995)
College of Southern Idaho
Twin Falls, ID 83301

Sound Beginnings

Kansas Resource Guide for Families with Infants and Toddlers who are Deaf/Hard of Hearing
Early Intervention Task Force (2001)
Kansas Commission for the Deaf and Hard of Hearing
3640 SW Topeka Blvd., Suite 150
Topeka, KS 66611-2373

Texas Connect Family Resource Guide

The University of Texas at Dallas
Callier Center for Communication Disorders
1966 Inwood Road
Dallas, TX 75235

Wisconsin Association for Perinatal Carewww.perinatalweb.org

1010 Mound Street
Madison, Wisconsin 53715